Information Management Enhancements to Improve Texas Cancer Data for Comprehensive Cancer Control

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Executive Summary

Cancer information management and process issues influencing comprehensive cancer control were reviewed with key stakeholders across the state. Stakeholders and experts in cancer surveillance, behavioral research, medical education, and patient care provided detailed insights and documentation on existing data collection, database management, and analysis processes. For the most part, cancer data on behavioral risk factors, educational interventions, and other public health functions are available in Texas, thanks to support from the Centers for Disease Control and Prevention, the Texas Cancer Council, state medical schools, Texas Department of Health, and other sources.

The most formidable gap in Texas cancer data exists in cancer incidence data, which do not meet federal certifications for timeliness, accuracy, and completeness. To address this gap, focus groups were conducted with cancer reporters from small, medium, and large hospitals, as well as those supporting rural communities to identify key issues and suggestions on how best to mitigate data quality issues pertaining to population-based cancer incidence. Focus groups were also conducted with physicians, information management professionals, Texas Cancer Registry system users, government and regulatory agency officials, and members of affiliated professional constituent groups. The information pertaining to cancer registration deficiencies are portrayed in this report within the context of an inventory of other catalysts and factors in cancer control, including other data sources as well as programs, agencies, and other resources.

The information gathered from the key TCR stakeholders yielded several overarching themes that were common among numerous respondents. Some of the most commonly reported TCR information management and process issues are those to which solutions could be relatively straightforward to implement. These include a comprehensive and consistent effort aimed at improved education of TCR reporters on issues such as the importance of complete and accurate cancer case reporting. In addition, improved awareness of TCR guidelines, improved access to these guidelines, and the appropriate use of guidelines in case reporting is likely to yield more appropriate and consistent reporting.

The simplest solution for fostering improved communication with TCR reporters is through the TCR Web site. In addition to the guidelines and reporter information currently available on the site, the TCR should include information highlighting the importance of complete and accurate cancer information as well as enumerate the various research activities generated from the TCR data. A listserve function could be used to ensure important information is disseminated to all TCR reporters via e-mail or through postal mail. The TCR Web site could also serve as a central source for summary cancer reports and graphs. Ultimately, a central Web site should be created to serve as a central point of contact for all published and disseminated forms of cancer data and those entities that use cancer data in cancer prevention and control efforts. The TCR Web site could be enhanced to become this site, or another Web site could be created or enhanced to become the cancer gateway that provides a link to the TCR Web site.

Although these enhancements would be expected to bring about noticeable improvements in TCR data quality, ***the most substantial improvements will likely only be realized with considerable investment in a modernized TCR infrastructure***. This is necessary since there is a practical limitation to which the present SandCrab system can be effectively modified to take advantage of technological improvements that have evolved since the TCR software was originally designed. Consequently, the most meaningful and enduring improvements to TCR data quality will likely require a comprehensive re-design of the SandCrab software, as well as the adoption of improved processes, some of which are successfully being used by registry systems elsewhere.

The enhanced SandCrab software should be built upon a more powerful and scalable database platform that would enable the TCR to fully take advantage of evolving technologies (such as networked computing over the Internet) and support more users and larger quantities of data. The enhanced TCR needs to support the current processes and any desired enhancements in one well-integrated system. This system could be designed to improve quality assurance through automated de-duplication algorithms and have a modular design that would allow other features to be added as requirements evolve. In addition, the enhanced system should allow for more interactions with reporters by allowing direct transmissions of data and receiving feedback electronically. Longer-term improvements, such as integration of data from electronic medical records, are likely to become worthwhile for the TCR as technology enhancements become commonplace among the submitting facilities.

The technical architecture of the enhanced TCR should probably be centralized, based on the information gathered for this study, the experiences of cancer registries in other states (e.g., California and Louisiana), and other statewide public health registries. However, it is important to note the distinction between a centralized technical architecture and the TCR processes that will utilize that system. It is recommended that regional TCR coalitions continue to address local reporting and feedback needs and provide the focused support necessary to ensure that rural communities have a viable mechanism for case reporting. One model worthy of further consideration is the regional contracting of the TCR, such as in California, where guidelines are established to foster standards for the consistent and appropriate management of registry information by regional agencies under contract to the state.

An important aspect of the enhanced TCR system is not only the enhanced software, but also a communications architecture that is in keeping with the present and anticipated demands for network connectivity to the system. Without it, even the most advanced TCR software is of limited value to stakeholders across Texas. To derive optimal benefit, there must be reliable and prompt access to the system for data submission and report verification. The network communication demands will become increasingly important as hospitals shift from the current emphasis on paper-based patient records to more electronic data transmission.

Given the scope of a comprehensive upgrade of the TCR software and related infrastructure, it is anticipated that resource availability, as well as the design and implementation, will require a replacement project with a multiple year horizon. Consequently, the TDH may wish to implement some near-term solutions that focus on TCR improvements that can be realized while the replacement project is underway. These may include options such as improved TCR reporter education and

feedback mechanisms, as well as near-term solutions to mitigate data quality problems and the labor costs associated with manual de-duplication of reported cases.

Factors Affecting Quality in Cancer Registry Systems

This section describes factors that have an impact on cancer registry system quality. The experiences of cancer registry systems in other states have been included here to demonstrate the effect of these factors.

State Statutes for Reporting Cancer

State cancer registries are able to receive complete, timely, and quality cancer incidence data through state legislation requiring providers of healthcare to submit the information to the state. Several model statutes for enforcing reporting requirements are available to cancer registries throughout the U.S.

California is among the most successful states in achieving reporting compliance due to both financial penalties to address noncompliance and the ability of the registry to recover costs for collecting unreported data. In the case of Connecticut, failure to comply with cancer reporting requirements may result in suspension or revocation of the hospital, clinic, or laboratory license. New Jersey law requires that data submissions to its registry be completed by a certified tumor registrar. Non-reporters in New Jersey are subjected to a financial penalty of up to $1,000 per business day. New Jersey also allows its registry to recover costs associated with the collection of unreported data.

In addition, many states require cancer reporting of their healthcare practitioners. The CDC indicates that of the 46 state cancer registries it funds through the National Program of Cancer Registries (NPCR), 40 of those states are in compliance with Public Law 102-515 (federal statute) requiring reporting by physicians and other healthcare practitioners. All states funded by the NPCR are required by this law to have in statute reporting of cancer cases by healthcare practitioners.

Currently, Texas statutes regarding cancer reporting indicate that hospitals, cancer treatment centers, and clinical pathology labs shall report, while physicians, ambulatory surgery centers and others *should* report. To rectify the situation, a bill has been filed in the Texas Legislature to require reporting by physicians involved solely in the diagnosis and treatment of cancer. Under the bill, ambulatory surgery centers and dentists also would be required to report.

Resources for Population-Based Cancer Registration

Large variations exist regarding the level of support and resources provided to cancer registries across the country. The geography, demographics, number of reporting sources, and cancer caseload of the state all dictate the workload for a registry to be able to maintain quality, timely, and complete data. Without adequate resources to address all of the above factors, a registry will be unable to provide the essential data needed for cancer prevention and control.

The following table outlines some of the factors listed above for some states as comparison along with their NAACCR certification rating. The NAACCR develops and promotes uniform data standards for cancer registration and certifies population-based registries. It should be noted that the NAACCR certification rating ranges

from Not certified, certified Silver or certified Gold, with Gold representing a successful accomplishment of all of the NAACCR requirements for an effective cancer registry.

The following table represents information that the Cancer Data Workgroup was able to gather through personal communications with various cancer registries across the nation:

State	Population	Caseload	Number of Facilities	Funding	Per Capita Cost	Cost per Cancer Case	NAACCR Certification
Connecticut	3.3million	18,500	42	$2.1 mil	$0.64	$114	Gold
Illinois	11.8 million	56,000	370	$1.5 mil	$0.13	$27	Gold
Louisiana	about 4.4 million	18,500	165	$1.2 mil	$0.27	$65	Gold
Minnesota	about 4.8 million	21,000	156	$1.3 mil	$0.27	$62	Gold
New Jersey	8.2 million	40,000	100	$1.6 mil	$0.20	$40	Gold
California	32 million	135,000	1,520	$8 mil*			Gold
Texas	20 million	76,000	470	$2 mil	$0.10	$26	Not Certified

* Excludes NAACCR funds.

Current state funding for the Texas Cancer Registry is approximately $900,000 annually, supplemented with $1.1 million in CDC funding under the NPCR. In actuality, the intent of the NPCR is to enhance existing cancer registries' functions beyond what is capable under state funding and to promote utilization of registry data. In Texas, the NPCR funding is used primarily to support infrastructure, due to insufficient state funding.

Having access to a population-based, statewide cancer registry is critical for behavioral and epidemiological researchers seeking federal grants to support their efforts. Since 1990, California cancer registry officials have documented that at least 382 publications using their cancer incidence data have appeared in peer-reviewed journals or as book chapters. In addition, California has received more than $203,916,199 in total cancer research grant funds since 1988, with $179,143,040 of that being federal funding based on its statewide cancer registry. California established a statewide cancer registry in 1988. Texas established a statewide cancer registry in 1995.

The cancer research efforts improve the knowledge surrounding cancer prevention and control and can improve patient care and provide information needed to protect the public health. For example, the Kentucky cancer registry used cancer data to identify districts within the state with high proportions of women having invasive cervical and late stage breast cancer. Through community outreach programs, Kentucky officials have targeted these areas for increasing Pap smear screening services and breast cancer screening.

Texas matched cancer registry data against the state's registry for HIV/AIDS to investigate the incidence of lung cancer in HIV and AIDs-infected patients. In addition, Texas has used cancer registry funds to collect and report childhood cancer incidence rates for the years 1991-1999. The childhood cancer incidence rates are used as reference for research of clusters of childhood cancers.

In San Antonio, Texas, cancer incidence rates were used to evaluate a cluster of reported liver cancer increase. The Texas Cancer Registry responds to more than 60 reports a year on cancer clusters and uses cancer incidence rates as a basis for investigation.

Cancer Registry Administration and Structure

A registry located within a state agency such as the TDH is required to follow the administrative policies set by the Texas Legislature for state agencies. As a result, the TCR is subject to, and consequently limited by, arbitrary limits on travel and staffing available to programs within the TDH and other agencies. Other models are in operation in registries across the country. The following table provides an overview of state cancer registry structures during 2000. The Cancer Data Workgroup was able to gather through personal communications with Dr. Vivien Chen, President elect NAACCR.

Exhibit G-1: Overview of National Registry Administrations and Structures

Number of States	Registry Administration and Structure
37 States	Registry program operated totally by state health department.
2 states and DC	Registry program within the health department but contract the majority of work to university.
4 states	Registry program within health department but contract all of the work of some state regions to university.
7 states	Registry program within university and operated totally by university.

Evolving Data Standards

A registry must be able to collect additional data variables, modify coding schemes, and revise reporting formats in keeping with refinements to reporting standards set by the North American Association of Central Cancer Registries (NAACCR). Other evolving standards affecting data interpretation include changes in the year 2000 standard population used for data analysis and changes in the diagnosis coding scheme for mortality data.

Data Sources for Comprehensive Cancer Control

Statewide Population-Based Cancer Registry (Data Source)

As mentioned above, the TCR is administered by the TDH. The TCR is a legislatively mandated, statewide, population-based registry that was established in 1979. For a period of two years in the late 1980s, the Texas Legislature de-funded the Texas Cancer Registry. The registry builds cancer incidence data from case reports it receives and analyzes mortality data received by the Bureau of Vital Statistics, TDH. The registry analyzes and publishes cancer incidence, mortality, and staging data for Texas. Data published by the TCR are used by the public, cancer researchers, health professionals and others and are used in the planning and implementation of cancer prevention and control initiatives. Cancer surveillance and reporting is one of the essential public health services carried out to promote and protect public health.

Vital Statistics Information

The Bureau of Vital Statistics within the TDH is the source of birth and death data related to cancer in Texas. These data are shared with the TCR for detailed analysis and studies on cancer.

Demographic Information

The Office of Health Policy and Planning within the TDH is the source of population and other data needed for both the calculations of rates, race/ethnic distribution, socioeconomic status, and other factors. Population data by age, sex, and race/ethnicity represent the standard 1990 Bureau of Census classification by race/ethnicity.

Behavioral and Risk Factor Data

Risk factor data are provided by the Texas Behavioral Risk Factor Surveillance System (BRFSS). The effort is collaboration between the Centers for Disease Control and Prevention and the Texas Department of Health. Data are collected on a regular basis through telephone survey in randomly sampled adult populations. Studies have been conducted on a number of cancer-related subjects and can be compared to results of other state BRFSS programs. Surveys can also be commissioned for a nominal fee from the TDH. The TDH also conducts Youth Behavioral Risk Factor Surveys, focusing on tobacco use and related subjects.

Databases of Treating Facilities and Providers

The Texas Cancer Data Center (TCDC) provides online cancer information on health professionals, facilities and services, cancer statistics, population, and community resources. The Texas Cancer Council funds the TCDC.

Catalysts for Comprehensive Cancer Control

State Cancer Plan

The Texas Cancer Council (TCC) is charged with developing, maintaining, and implementing a statewide plan to prevent and control cancer. Through its plan, the TCC affirms that all citizens should receive culturally appropriate information and services about cancer risk reduction, prevention, screening, diagnosis, treatment and rehabilitation. In addition, the TCC, through the Texas Cancer Plan, forges public/private partnerships at the state and local levels to reduce the impact of cancer on Texans.

State Agency or Program Devoted to Comprehensive Cancer Control

The Texas Cancer Council is the state agency dedicated to reducing the human and economic impact of cancer on Texans through the promotion and support of collaborative, innovative, and effective programs and policies for cancer prevention and control. The TCC was formed in 1987 as the result of a Legislative Task Force on Cancer. As mentioned above, the TCC is responsible for maintaining and implementing the Texas Cancer Plan.

In addition, TDH currently has in place a Comprehensive Cancer Control Coalition, a newly formed effort funded by the CDC.

Advisory Expertise for Cancer Planning and Service Delivery Through State Agency(ies)

Texas' state agency devoted to cancer prevention and control has in place a formal, appointed board of directors to guide its implementation of the Texas Cancer Plan. In addition, TCC projects have in place numerous steering committees and advisory bodies to guide project activities. Similarly, through the newly formed Comprehensive Cancer Control Coalition and through programs such as the Prostate Cancer Advisory Committee, the Breast and Cervical Cancer Control Program (BCCCP), and the Office of Tobacco Prevention and Control's Tobacco Prevention Task Force, the state is able to gain input and direction on activities to target certain cancers and populations at increased risk. Leadership from medical, nursing, and dental schools and volunteerism among healthcare professionals and educators are also key resources.

Cooperative Atmosphere

Coordinated efforts exist across TDH programs and other partners. Registry data were used to demonstrate the need for the BCCCP in Texas. The TCC and its programs, such as the Physician and Nurse Oncology Education Programs have worked with the TDH's Prostate Cancer Advisory Committee and the BRFSS program to develop complementary surveys on prostate cancer knowledge among physicians, nurses, and the public. The goal of this collaborative effort is to reduce the unequal burden of prostate cancer among African American males in Texas as identified by the Texas Cancer Registry.

Active Voluntary Health Organizations for Cancer

The American Cancer Society of Texas collaborates on a number of activities, including long-standing partnership with the TDH's Office of Tobacco Prevention and Control to use Youth Behavioral Risk Factor Surveillance System (YBRFS) and TCR data to design programs and campaigns to address tobacco use in Texas. The American Cancer Society (ACS) and the TCR worked in tandem to produce the first-ever Texas Cancer Facts and Figures, modeled after the national publication of the ACS, Cancer Facts and Figures. In addition, these data are being used for community assessments throughout Texas for strategic planning of ACS activities at the local level. Other important voluntary activities of special importance within Texas include the Intercultural Cancer Council, Susan B. Komen Foundation, Lance Armstrong Foundation.

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1.0 Introduction

The Texas Cancer Registry (TCR) is a legislatively mandated statewide population-based registry that was established in 1979. The registry builds cancer incidence data from case reports it receives and analyzes and publishes cancer incidence, mortality, and staging data for Texas. Data published by the TCR are used by the public, cancer researchers, health professionals and others and are used in the planning and implementation of cancer prevention and control initiatives. Cancer surveillance and reporting is one of the essential public health services carried out to promote and protect public health.

The TCR is essential to the tracking and reporting of statewide cancer morbidity information. In addition, the TCR analyzes and reports cancer mortality information made available from the Bureau of Vital Statistics, Texas Department of Health.

In recent years, it has become evident that the TCR has difficulty providing timely, accurate, and complete cancer morbidity and mortality information on a consistent basis. Given the vital role the TCR plays in the surveillance of cancer throughout the state, this shortcoming is of great concern to the Texas Department of Health (TDH), the Texas Medical Association (TMA), the Cancer Data Workgroup, and all healthcare professionals dedicated to the treatment and prevention of cancer in Texas.

Recently, the Centers for Disease Control and Prevention (CDC) renewed their Cooperative Agreement with the TDH under the National Program of Cancer Registries (NPCR) and have encouraged the TDH to focus efforts on addressing a variety of TCR data quality issues. This report is a compilation of the basic information management and process issues that challenge the TCR and recommendations on their remediation.

The information management and process issues were identified through an internal systems assessment of the current TCR infrastructure. This was achieved by interviewing various stakeholders involved with the TDH, the TMA, the TCR, and other cancer registries. This report enumerates the technical and process issues that were identified, along with recommendations for improvement.

2.0 Background

The burden of cancer in Texas is substantial and the importance of cancer surveillance has never been greater. During the course of this year, it is estimated that over 79,000 Texans will be diagnosed with cancer and over 34,000 cancer deaths will occur. Cancer surveillance is a fundamental component of the strategies employed to control and reduce morbidity and mortality from this deadly family of diseases.

Effective cancer surveillance provides the link between the identification of behavioral and environmental risk factors, which is vital to the prevention of cancer and subsequent reduction of the burden of cancer. Identifying the incidence and prevalence of cancer within a population is a fundamental step toward effective intervention by public health agencies and medical care delivery organizations. Although the identification of incident cases is essential, it is equally important that these cases be accurately tracked in order to determine the duration of illness and hence the prevalence of cancer within Texas. A cancer registry is the foundation for cancer prevention and control.

Several factors influence the potential effectiveness of a cancer surveillance system. In order to be effective, a statewide cancer registry requires several essential processes be in place. A key assumption underlying effective cancer surveillance is that accurate and complete cancer information is reported in a timely manner to the registry. Once cancer information is reported to the TCR, it is further assumed that processes are in place to ensure the validation and dissemination of this information to public health and medical care delivery organizations.

2.1 The Current TCR Infrastructure

The TCR gathers cancer morbidity and mortality information in a statewide database, which is supported by operations located at five regional offices. Though the majority of facilities report information through electronic means, nearly one-third of facilities submit information to the registry in some type of paper format. As a consequence, considerable effort is consumed in manual data entry, editing, and correction of cancer information using connectivity to the central TCR management database in Austin.

Evidence suggests that reporting methods are related to facility size; facilities with smaller cancer caseloads tend to report cancer case information in paper-based formats. Further, the North American Association of Central Cancer Registries (NAACCR) audit of 1997 TCR data indicates that the completeness of case ascertainment is associated with facility size, since low-caseload facilities had reported only 85 percent of their cases.

A recent review of the TCR considered these issues and identified several data quality concerns that indicate the need for improvements to the TCR information management infrastructure and related processes. In particular, the issues that are directly related to information management include:

- completeness of case ascertainment,
- volume of death certificate-only cases,
- magnitude of duplicate primary cases,
- timeliness and TCR record processing, and
- quality assurance of data submissions.

A near-term outcome of these issues is the recent CDC decision to reduce the funding level of the TCR Cooperative Agreement with the TDH. More fundamentally, these data quality issues can substantially affect the reliability and validity of information based on the TCR and undermine its effectiveness in the prevention and reduction of cancer in Texas.

2.2 The Role of the Cancer Data Workgroup

In September 1998, the Texas Medical Association formed the Cancer Data Workgroup to address deficiencies in the timeliness and accuracy of cancer data for the state. This workgroup is equipped with experts from Texas medical schools, schools of public health, major cancer centers, facilities and facility systems, cancer registration, oncology, pathology, surgery, pediatric oncology, family medicine, and organized medicine.

The workgroup has been administered by TMA since its inception, voluntarily meeting on a quarterly basis to examine and discuss cancer data needs in Texas. The multi-faceted nature of expertise represented in the workgroup is important because the factors affecting cancer surveillance cross over the public, private, and volunteer sectors of epidemiology, medicine, public health, medical education, and healthcare systems.

In addition, the Cancer Data Workgroup members and organizations are involved in the development and dissemination of cancer data through a number of other state cancer-related activities. A number of other critical data tools and entities are needed at the state level, to be used in tandem with statewide, population-based registry as a guide for strategic planning in cancer prevention and control. In Texas, these tools and entities include but are not limited to:

- a state plan for cancer control;
- a state agency devoted to cancer prevention and control;
- leadership from medical, nursing, and dental schools;
- voluntary efforts from healthcare professionals;
- active voluntary organizations for cancer;
- vital statistics information;
- demographic information;
- behavioral and risk factor data; and
- information on treatment facilities and providers.

The success of these components ultimately relies on the ability of the state cancer registry to contribute to national cancer data sets in establishing a point of reference for the relative success of state prevention and control activities.

VRI relied on input from the Cancer Data Workgroup in developing this document. Furthermore, the Cancer Data Workgroup provided additional information on:

- Factors Affecting Quality in Cancer Registry Systems,
- Data Sources for Comprehensive Cancer Control, and
- Catalysts for Comprehensive Cancer Control.

This information is included in this document as Appendix G: Additional Background Information.

3.0 Objective

Numerous barriers currently hinder efforts by the Texas Department of Health (TDH) to effectively monitor cancer morbidity and mortality. The objective of this report is to identify these barriers and define information management and related business process enhancements to the TCR that will improve the capturing and reporting of timely, accurate, and complete cancer morbidity and mortality information.

The central objective is to ensure that the TDH and TCR stakeholders (such as those represented by the Cancer Data Workgroup), can most effectively leverage the existing TCR infrastructure in a manner that is completely consistent with the Centers for Disease Control and Prevention's reporting requirements and information system standards.

4.0 Technical Approach

Vector Research, Incorporated (VRI) collaborated with a task force of the Cancer Data Workgroup to perform a comprehensive internal systems assessment of the current Texas Cancer Registry (TCR) infrastructure. The decision was made to obtain a thorough understanding of the existing TCR from the TCR staff and gain an understanding of the technical issues facing the TCR from various stakeholders involved with the TCR process. The information was gathered from these two groups by either face to face meetings or phone interviews. The following summarizes the information gathered from the TCR staff, the process used for stakeholder focus group development, and the information gathered from the meetings with focus group members.

4.1 Overview of TCR System

VRI met with the TCR staff to understand the existing TCR data collection, data entry, information storage/retrieval, database management, and analysis processes. This task was an important first step toward understanding the current TCR environment and was the basis for informed recommendations. The TCR staff also supplied VRI with appropriate documentation. Each step of the TCR process was examined, starting with current facility data collection, management, and reporting processes. The process used by the TCR to capture and track information reported by facilities was assessed, as were current error detection and resolution procedures. This assessment also distinguished those processes currently performed at regional TCR offices versus those performed at the central TCR office.

The models in Appendix A represent the high-level data and processes that describe the current TCR information architecture. These models provide a description of the information collected, stored, and reported by the TCR, as well as related processes. These models served as the baseline description of the TCR from which the recommendations in this document were made.

4.1.1 TCR Structure

The TCR is made up of five regional registries located in Arlington, Austin, Lubbock, Houston, and San Antonio. The central office in Austin houses the statewide registry database, called the Statewide Algorithm aND database for Cancer Registration and ABatement (SandCrab). The registry setup in Texas utilizes a statewide, centralized database architecture providing the regional offices access to the central database.

The regional offices are responsible for receiving non-electronically reported data from the facilities within their region and editing and correcting data reported by all facilities within their region. The regional staff members work with their facilities to ensure reporting compliance, train facility staff regarding data requirements of the TCR, and resolve conflicting data reported by two or more different facilities for the same cancer patient. The central office in Austin receives electronic submissions from all reporters in the state and is responsible for all data processing including

receipt of electronically reported data, record consolidation, data analyses, and report publication. Each regional office has online access to the TCR database to perform data editing and error resolution.

Almost half of the facilities that report to the TCR use the TCR-developed software SandCrab Lite for their electronic submissions, however these submissions do not account for half of the data in the TCR. Of the data submitted to the TCR:

- about 22 percent is submitted by reporters using SandCrab Lite,
- about 71 percent is submitted by reporters using various other cancer registry software systems,
- about 6 percent is submitted using the Confidential Cancer Incidence Reporting Form (TCR#1), and
- less than 1 percent is submitted by small facilities that send their medical records directly to their regional office.

The data gathered by reporters are sent via modem connection or on disk to the central office for incorporation into the TCR SandCrab software. The paper forms are sent to the regional registries, where regional office staff hand enter the medical record information into SandCrab or send the cases to the central office staff for data entry.

4.1.2 TCR Processes

When submissions come to the central office, the data go through a series of edits and a check to see if the patient is already in SandCrab. All new information on a cancer patient already in SandCrab is consolidated into the SandCrab system. Errors are sent to a separate database and the regional office staff is responsible for contacting reporters and correcting errors.

The central office also performs an extensive duplicate patient check biannually. It should be noted that the patient de-duplication and consolidation efforts are predominantly manual. As a result, the patient consolidation effort is a very time-intensive and arduous process that the TCR performs to ensure the most complete and accurate data are available for cancer patients in Texas.

The TCR also receives an electronic file with death records from the Bureau of Vital Statistics (BVS) in the TDH. The TCR staff uses the death record information to perform detailed cancer mortality analysis, identify SandCrab patients who have expired, and identify cancer patients that may not already exist in the SandCrab database. Cancer patients who are identified through the BVS electronic file are added in, if possible, by gathering additional information from the providers so the case is complete. If no information can be found on the patient, they are added into SandCrab as “death certificate only” cases with incomplete data. The TCR also receives geo-codes for patients’ places of residence from the TDH.

This is a very simplified summary of the data compilation process. The pictorial representation in Appendix A offers additional process detail.

5.0 Focus Groups

Focus group meetings were used to gather a systematic assessment of the information deficiencies perceived by key TCR stakeholders, building on the information available from the most recent NAACCR audit and consultant review. Although several fundamental data quality issues have already been outlined in these previous studies, this task focused on the underlying information management issues that disrupt timely, accurate, and complete TCR data.

5.1 Focus Group Objectives

The following represent the main objectives of the focus group meetings as determined by VRI and the Cancer Data task force:

1. Identify the issues or concerns of the person who provides the information.
2. Identify the issues or concerns of the institution that provides the information.
3. Identify the issues or concerns of the TCR receiver of information.
4. Identify the issues or concerns of the users of the information.

VRI consulted with the Cancer Data task force to obtain a list of appropriate contacts. The focus group assessments were performed as structured interviews, either face-to-face or via phone conference. VRI initially worked with the Cancer Data task force to identify the focus group categories on which to concentrate efforts. The following lists the final focus group categories:

- Reporters
- End Users
- Information Management/Information Technology (IM/IT) Personnel
- Professional Constituents
- Government Officials/Funders/Regulators

Within each of the focus group categories, VRI and the Cancer Data task force identified the types of members that should be involved and topics that should be discussed with focus group members. The listing of member categories and discussion topics are presented in Appendix B.

5.2 Focus Group Process

VRI used the focus group topics to develop stem questions for use during the structured focus group interviews. The stem questions were fielded by a pilot group of individuals involved with the TCR process. The pilot group helped identify the adequacy, applicability, and appropriateness of the stem questions for each focus group category. The pilot group members also identified additional questions that should be included for each focus group category to ensure a thorough evaluation of

the TCR process. Appendix C contains the final stem questions used during the focus group meetings. Appendix D contains the names of pilot group members who provided feedback on the stem questions.

Based on the points of contact recommended by various task force members, VRI next began conducting the focus group meetings. Meetings were conducted both face-to-face and via phone conference. Appendix E lists the focus group members who provided feedback to VRI.

In addition to identifying technical and process issues, the focus group members also made suggestions for improvement and described processes that worked well for them. This process information is also included in the document. Section 6.0 presents the issues identified by the various focus group members and recommendations to mediate these issues.

6.0 Focus Group Findings

Focus groups were conducted to gather the perspectives of TCR key stakeholders on technical and process issues. This section provides a summary of the findings from those sessions and is organized by the five categories of stakeholders with which focus groups were conducted:

- Reporters
- End Users
- Information Management/Information Technology (IM/IT) Personnel
- Professional Constituents
- Government Officials/Funders/Regulators

The focus group members raised many technical and process issues. The biggest inhibitor in reporting timely and accurate information from reporters was a lack of adequate funding and staff. Many of the hospitals and clinics are already so busy running operations that reporting to the TCR is a low priority. Many of the hospitals and clinics that do have adequate staff voiced concerns on how to keep up with the increasing incidence of cancer and the greater workload they may see in the future.

Many of the end users and professional constituents commented that their biggest issues were the lack of timely information from the TCR. The IM/IT Personnel at the TCR voiced a lack of adequate funds to incorporate technical solutions that would automate their data consolidation process. VRI relied on pending Federal and state legislation to identify upcoming "government officials/funders/regulators" issues that may be on the horizon for the TCR.

For each stakeholder group, a synopsis of key findings and recommendations made by focus group members is presented.

6.1 Focus Group Category: Reporters

A "reporter" is defined as anyone who reports or could potentially report to the TCR. VRI received input from staff who worked with small and medium hospitals, large clinic staff, medical center staff, large hospital staff, certified tumor registrars, hospital abstractors, pathologists, urologists, oncologists, physician office staff, and citywide registry staff. The comments are organized by the following categories of reporter:

- Small Hospitals and Rural Community Hospitals;
- Medium Hospitals;
- Large Clinics, Medical Centers, and Large Hospitals;
- Physician Offices; and
- SandCrab Lite Users.

6.1.1 Reporters at Small Hospitals (<100 Patients Annually) and Rural Community Hospitals

Issues Reported:

- **Participation Seen as a Burden**
- **Insufficient Staff or Staff Knowledge**

These issues and their recommended solutions are described below.

Participation Seen as a Burden

Whereas many larger hospitals choose to have an approved cancer program by the American College of Surgeons (ACoS), small hospitals and rural community hospitals are not very interested in receiving ACoS approval, since most do not have a cancer program. Being in an ACoS-approved program is voluntary for an institution. ACoS approval requires reporting that is somewhat more intensive than the requirements imposed by the state of Texas; therefore, reporting to the TCR is not an additional burden to an ACoS approved hospital. Since the smaller hospitals don't have cancer programs and are not ACoS approved, there is no direct benefit derived from gathering and reporting cancer information. Therefore, reporting cancer patient information to the state is seen as a large imposition for these smaller hospitals.

Recommendation: Although these hospitals do not see the direct results of reporting cancer information to the state, they need to understand the vital role the TCR plays in the surveillance of cancer throughout the state and the importance of complete and accurate cancer information. The smaller hospitals need to be made aware that cancer surveillance is a fundamental component of the strategies employed to control and reduce cancer morbidity and mortality. In addition, all reporters could be made aware of the importance of reporting accurate and complete cancer information during the regional facility training sessions.

Insufficient Staff or Staff Knowledge

One of the biggest problems facing small hospitals and rural community hospitals is that they are not staffed with personnel who understand cancer case finding or reporting. Due to inadequate funds for cancer reporting, adequate staff cannot be afforded. Many of the reporters interviewed felt it takes about two years of training to learn correct cancer reporting. The reporter also needs a good medical background to understand critical information such as the different sites of cancer and how to distinguish if a patient has more than one reportable case of cancer.

Due to a lack of adequate staff, the small hospitals often task a hospital clerk with performing case finding and reporting. There is a high rate of turnover in the hospital clerk position, thus it is hard to achieve any benefits of continuity and experience from staff in this position.

It is apparent that much attention needs to be given to the small hospitals to ensure that all cancer cases are being reported and that they are being reported accurately.

Randall/Potter County has overcome some of these issues by creating an almost countywide, shared registry (with the exception of one hospital, Northwest Texas Hospital) begun by Dr. Goldston in 1960. Randall/Potter County has some cities with large hospitals, surrounded by many rural communities with smaller hospitals. The bigger hospitals included in the Goldston registry are the Baptist hospital, VA Amarillo, and the Harrington Cancer Center. The Goldston registry is funded by the facilities that participate via a contract. The Goldston registry supports cancer conferences, cancer peer committees, cancer follow up, and annual reports. The registry also pays for the ACoS accreditation and is in charge of ensuring the requirements are met.

The Goldston registry is staffed with abstractors who collect all of the cancer information from the supporting hospitals. The registry staff receive disease index information from the hospitals. The registry staff use the disease index information to identify potential cancer cases at each hospital. The registry staff then visit the hospital, abstract the appropriate cancer information and enter the data on registry software on their laptops. A per-case amount is charged for each case abstracted.

The registry staff receive the comprehensive pathology reports from the pathologists tied to a contracted hospital. In addition, the registry staff also receives the radiation summaries from the Harrington Cancer Center.

Rural communities participated in the Goldston registry up until the 1970s; however, the rural communities are not currently included in the registry. It is the intent of the Goldston registry to incorporate the rural communities to create a more complete countywide registry. The registry has not resolved how to charge the rural communities for abstracting their cases. Members of the Goldston registry speculate that it will either be a no charge option (especially if the patient eventually ends up being referred to one of the bigger facilities) or a discounted rate. The registry will then pick up the difference in cost to pay the abstractors.

The President and Medical Director of the Harrington Cancer Center, commented that an advantage of citywide registry is that it facilitates local buy-in and "ownership," which promotes accuracy of data. The medical director felt that a great deal of the rural communities may be suspicious of reporting to a statewide registry but found a local registry safe and personal. The reporters also have more access to the data, so there is interest in reporting accurate and timely information. Also, all of the responsibility for reporting falls on the medical center.

Recommendation: The short-term objective should be to educate small hospitals on how to perform cancer case finding and allow them to fax or send the entire patient medical record to the regional office, as is currently being done. TCR staff members commented that they have spent considerable time training personnel in hospitals to perform casefinding; however, the rapid turnover in trained staff has negated any progress in this area. To retain the benefits of training, hospitals should be encouraged to identify a more stable staff position in the medical records department to receive the cancer reporter training.

The TDH and TCR stakeholders should encourage and enable cities with large medical centers surrounded by rural communities to set up some type of local

countywide registry. A local countywide registry would enable a group of reporters to pool their resources and report in a unified manner to the TCR.

The medical center could initiate the collection of complete and accurate cancer information from all participants. The medical center could hire certified tumor registrars to gather the information and enter it into the local countywide registry. Since a certified tumor registrar would be gathering cancer information, it will save the regional registries a great deal of potential work in the long run from researching information submitted from rural community hospitals, which may not have skilled staff to submit correct cancer patient information.

Ideally, the state should develop guidelines on where it is and is not appropriate (by population) to set up local registries. One consideration might be the percentage of county residents who are diagnosed or treated in the given county.

The TCR could use the multiple database regional registry requirements used by California as an example to provide some guidance to the local countywide registry developers. The Official California Code of Regulations implements the state statutes and has the same force of law as court decisions or legislation. The California Cancer Registry must comply with section 2593 of the Official California Code of Regulations (Appendix F).

Small hospitals that are not able to participate in a local countywide registry should consider hiring a certified tumor registrar to perform their cancer reporting. On a monthly basis, the small hospital could send a list of all patient disease indexes to the certified tumor registrar, who in turn could determine which patients were eligible for submission into the TCR and then abstract this information from the small hospital. The certified tumor registrar could then submit the cancer information to the TCR on behalf of the small hospital.

It might be easier for a group of hospitals to pool together and hire a certified tumor registrar to gather their information. It was mentioned that there may not be enough certified tumor registrars available in the state of Texas. The TDH and TCR stakeholders might be able to work in tandem with the small hospitals to attract certified tumor registrars. Small hospital participation could also be solicited in a region to ensure that there was enough work to support a certified tumor registrar.

With the onset of technology, many hospitals are moving to electronic medical records. When small hospitals are at the point of using this technology, it would be appropriate to incorporate an export feature that would identify the cancer-related disease indexes. All medical records that are cancer related could then be automatically exported to a contracted certified tumor registrar or the TCR regional office. This would be a longer-term goal that would depend on the technology being used at small hospitals.

It should be noted that VRI is not recommending that small hospital and rural community hospital staff undertake the task of abstracting their medical records and submitting information via a cancer registry. Since small hospitals and rural community hospitals commonly do not have staff trained in cancer reporting, it is prudent to allow hired certified tumor registrar staff trained in cancer reporting to perform this function.

6.1.2 Reporters at Medium Hospitals (100–300 Patients Annually)

Issues Reported:

- **Participation Seen as a Burden**
- **Insufficient Staff or Staff Knowledge**

These issues and their recommended solutions are described below.

Participation Seen as a Burden

Some of the medium hospitals do not have cancer programs and they are not ACoS approved. Therefore, these specific hospitals also see cancer reporting as a burden to their current workload. There is no direct benefit that these reporters derive from gathering and reporting cancer information to the TCR.

Recommendation: Once again, increasing the medium hospital staff knowledge of the importance of cancer reporting is key in gaining participation. All reporters need to be made aware of the importance of reporting accurate and complete cancer information during the regional facility training sessions.

Insufficient Staff or Staff Knowledge

Like small hospitals, medium hospitals face a high turnover of staff, which makes it difficult to remain staffed with personnel who understand cancer case finding. The medium hospitals are also short on the funds necessary to retain staff proficient in cancer reporting, which results in staff untrained in proper reporting. Medium-sized hospitals are likely to have a large number of cancer patients. Receiving the entire medical record from this group would generate significant data entry work for the regional offices.

Two Laredo hospitals have used a method that would be useful in assuring complete and accurate information from these hospitals. A certified tumor registrar receives a listing of all of the diagnosis codes that are incurred from patients for each month for the Doctors Hospital of Laredo and the Mercy Regional Hospital in Laredo. The certified tumor registrar then goes through this list to identify potential cancer cases. The certified tumor registrar visits the hospitals once a month and abstracts the cancer patient information and enters it onto registry software on a laptop. The Laredo hospitals have been using this method for the past three years and have rarely been called with questions from the TCR regarding their submissions.

Recommendation: The medium hospitals should send monthly disease index information to a contracted certified tumor registrar. The certified tumor registrar could then visit these medium hospitals monthly to abstract information and perform cancer reporting on behalf of the medium hospital. A longer-term goal would be to use the electronic medical records example listed above for small hospitals. When the medium hospital infrastructure incorporates electronic medical records, it would be appropriate to export all of the medical records that are cancer-related to the contracted certified tumor registrar. The certified tumor registrar could then enter the relevant information into cancer registry software and then send it to the TCR. This process saves the certified tumor registrar from making a physical trip to the hospital.

A number of medium hospitals should pool together and hire a certified tumor registrar to gather their information. The TDH and its stakeholders might be able to work in tandem with small and medium hospitals to attract certified tumor registrars. Small and medium hospital participation could also be solicited in a region to ensure that there was enough work to support a certified tumor registrar.

It should be noted that due to a lack of personnel intimately familiar with cancer reporting at medium sized hospitals, it does not seem appropriate for medium hospitals to do their own reporting.

6.1.3 Reporters at Large Clinics, Medical Centers, and Large Hospitals

Many larger hospitals and clinics are ACoS certified and many of the reporting requirements for the ACoS are more intensive in terms of collecting follow-up information, thus reporting to the TCR is not much of an additional burden. The TCR does require some additional types of cancer patient information that the ACoS does not, though this does not seem to pose a great deal of additional work for the reporters.

Issues Reported:

- **Insufficient Staff and Technology**
- **Lack of Electronic Linkages to Different Sources of Data**
- **Reporters Apathetic About Reporting**
- **Reporters Want to See TCR Data on Their Patients**
- **Reporters Unsure of Proper Cancer Reporting**
- **Duplication of Effort When Facilities Submit Data for the Same Patient**
- **Reporters Discouraged That Submissions May Not be Processed in a Timely Manner**

These issues and their recommended solutions are described below.

Insufficient Staff and Technology

Many of these reporting entities do not have adequate funds to hire enough staff to properly accommodate all of the work that goes into cancer reporting. Reporters often hand code the entire medical record, including patient demographics, into the cancer registry. Although they would like to automate their processes, funding has prevented the incorporation of useful technology.

Some reporters mentioned they are able to keep up with the current influx of patient cancer information with their manual data entry process, but with increasing population size, it is suspected that incidence of cancer will increase also. These reporters expressed concerns about keeping up with potential increases in cancer incidence if funding doesn't increase as well.

Recommendation: Although adequate funds may not be available for distribution, reporters can be educated to become more efficient in their cancer reporting. The

TCR should encourage the various types of reporters to share their best practices for gathering and submitting cancer information. The reporter community can learn from each other and improve their current processes, which will increase efficiency. The regional office staff could gather this information and present it to the various reporters during in-services and training sessions. Such a practice would improve reporter involvement and participation. This should also benefit the current cancer reporting process, since reporters will gain a sense of involvement with the TCR. Increased regional staff involvement with reporters where best practices are pooled and shared with the reporter community will allow reporters to perform their function more efficiently.

Lack of Electronic Linkages to Different Sources of Data

Many larger facilities lack the appropriate technical infrastructure to easily gather all of the cancer data that lie within their different affiliated facilities. Often these reporters must physically travel to associated facilities to abstract additional patient cancer information to make a complete patient cancer report. Also, medical centers may be dispersed, which causes difficulty receiving information from their supporting physicians. Although they are aware of the problem, these facilities do not have the funding or infrastructure to alleviate the problem.

Shannon Medical Center in St. Angelo seems to have overcome some of the problems associated with gathering information from physicians out of their physical reach. The physicians who belong to Shannon Medical Center send an e-mail of their dictated notes to the cancer program coordinator at Shannon Medical Center. In this way, the cancer program coordinator is aware of where patients will be treated and what treatment they will receive. The staff of the Baylor Medical Center cancer registry receive a hard copy of the pathologist report and an electronic copy of the dictated oncologist report.

Recommendation: Reporters at these larger facilities need to encourage all of their physicians to send their cancer information to their facility of affiliation. This will enable the larger facilities to capture a true picture of the cancer incidence and treatment associated with their facility. There are opportunities, such as having physicians send in dictated notes or the entire physician medical record that can be evaluated for feasibility.

It should be noted that larger facilities may not have the resources to incorporate all of the physician information into their registry system. Therefore, in order to fulfill this recommendation, the larger facilities may have to hire additional staff to incorporate the affiliated physician cancer information.

Once the state mandates physician reporting, the collection of this information will be easier since larger facilities will have legal backing for their demands for physician cancer information. Additionally, larger facilities can then offer to collect the information for physicians and send it on to the TCR.

Another option for the TCR is to incorporate active regional participation in physician data collection. This process would require that regional staff actively gather physician information from the physician offices. The California Cancer Registry (CCR) incorporates a similar method, in which the regional registry staff

members actually go to small hospitals and physician offices and perform abstracting. The framework of the CCR, a multiple database regional registry, is detailed in Section 7.1. However, it should be noted that the California Health and Safety Code requires that each diagnosis of cancer made in the state be reported to the CCR. This includes physicians, dentists, podiatrists, and other practitioners.

California physicians report the following information in a diagnosis report called the CMR: Name, Phone, Race, Ethnicity, Gender, Age, Date of Birth, Social Security Number, Address, Disease, Date of Onset, Reported by (professional's information and license number), Date of Death, and Date of Diagnosis. These reports are mailed or faxed to the regional registries. It should be noted that the physicians have to report on patients not previously admitted as an inpatient or outpatient to a California cancer-reporting facility for primary care or patients that are referred by the physician to a hospital or cancer-reporting facility for diagnosis or treatment of cancer.

Within approximately six months of the report, an abstractor from the region is sent to the professional's office to gather clinical data. Physicians reporting small numbers of cases may be sent a Physician Office Report form from their Regional Registry to complete. Some physicians are never contacted regarding a case because the case has been reported by another source. California law requires that pertinent medical records be made available to abstractors, though provisions exist to protect the confidentiality of patients.

Although the TCR does not have the multiple database regional registries, given the proper amount of staff at each region they would be able to perform such a task and gather all of the physician information that had not been reported by another facility. The TCR would likely need to hire additional staff to incorporate active regional participation in data collection.

Reporters Apathetic About Reporting

Reporters are not fully aware of what the state is trying to accomplish with the TCR or what obstacles the state faces in gathering good cancer information. Many reporters are also unaware of the research that is generated from the cancer database. There is a pervasive misconception that the TCR only performs incidence reporting. Reporters were curious why they had to report so much information to the TCR when the TCR only produced cancer incidence rates. Unfortunately, the reporters are not aware of the various manners in which the TCR data have been used, nor the benefits these data have provided to cancer surveillance research. These impressions and misconceptions have led to some apathy in reporting to the TCR.

Reporters in the Lubbock region gave very positive feedback on their involvement with the regional staff and their TCR reporting process. Apparently, the Lubbock regional staff provides reporters with feedback sheets on the reporter submissions that clearly outline the potential errors and their solutions. Reporters found these to be invaluable and good teaching tools. Lubbock regional staff also provides a great deal of in-services that the reporters found to be very educational and useful. Some of these in-services entailed educating reporters on why certain pieces of information are gathered, with an explanation on what the TCR does with the information. Reporters admitted to feeling better about reporting to the TCR when they understood the relevance of each data element. In addition, the Lubbock regional

staff sends out little "extras," like calendars, to the reporters with whom they work closely. The reporters expressed a great feeling of satisfaction and enjoyment in working with and reporting to the TCR due to their involvement with the Lubbock regional staff. One reporter said that she got back as much from reporting to the Lubbock region as she put into reporting. Lubbock was the only region with reporters who specifically expressed great pleasure in reporting to the TCR.

Recommendation: The reporters need to understand that there is a great deal of medical and epidemiological value in the TCR data. Not only are the cancer data being used to assess the incidence of cancer, but for monitoring cancer incidence and stage, developing and targeting resources, evaluating treatment alternatives, and measuring the success of cancer screening programs. Because of the size of Texas' population and its racial and cultural diversity, the TCR offers unique opportunities to assess cancer risk factors and stage at diagnosis among ethnic groups. One end user mentioned that she would like to see reports on what types of research is being done with the TCR data because it might generate more ideas on other research that could be done.

The TCR could add this information in the *Texas Cancer Reporting News*. This newsletter was created to keep reporters abreast of cancer reporting requirements, share current happenings and upcoming events, and serve as a training source for cancer reporting by the use of such features as cancer reporting hints. The *Texas Cancer Reporting News* is published three times a year and is available on the TCR Web site.

The regional offices should also convey the importance of the cancer registry to reporters during in-services, training sessions, and meetings. The TCR should look to increase regional involvement with reporters to minimize reporter apathy. It is evident that education and the little "extras" go a long way in gaining reporter trust and cooperation. In addition, it would give reporters an opportunity to voice their concerns and questions with some of the reporting processes. If reporters understand why they are reporting a certain data element, they are more apt to report more accurate data. In addition, some reporter concerns may have already been addressed in the reporting guidelines. Sometimes it is just a matter of educating reporters on the proper way to report for some of the more unique situations.

Many reporters stated that they felt that education would increase reporting since the reporters don't recognize the significance of their reporting and the reporters don't understand why the TCR is asking for the data that they request. It may be a case of helping the reporters so they can in turn help the TCR.

One area where many reporters may need improvement is in cancer case finding skills. One reporter suggested that the state should couple their case-finding training with the upcoming International Classification Disease-10 training. This could also be done at the regional level.

The TCR may need to hire additional staff at the regional level to support the reporters directly.

Reporters Want to See TCR Data on Their Patients

As mentioned above, some of the reporters admitted to being apathetic about reporting to the TCR. These reporters do not feel as if they are a part of the registry, since they are unable to get any additional information on patients for whom they submit information. Reporters admitted to not sending in corrections to their submissions since they felt the state might not incorporate their changes. Reporters seemed to not care about data quality since they had no access to it and could not use the data for patient care purposes. Reporters also voiced frustration in having to buy reports from the TCR for patient information they submitted. It should be noted that the TCR staff confirmed that the reporters do not have to pay for reports summarizing the cancer information they submitted, or for a return of the original information they sent the TCR. Therefore, this may represent a need for clarification on the resources available to reporters at no charge.

Many of the reporters stated that they would gain value from the TCR and be motivated to report if they were able to access the TCR database to research information on their patients. Reporters said they felt like they provide so much to the state registry but don't get to reap the benefits of a comprehensive cancer database.

There are instances when a patient will come to a hospital and expire soon after arrival. In such cases, it is difficult for the hospital to gather initial diagnosis information. Also, many reporters would like to get timely information when one of their patients expires at another facility. The Social Security death index is used by many of the reporters, though reporters suspect the state gets much more current information. Some reporters said that they needed to know death information as quickly as possible for survival analysis studies they perform. In addition, many of the hospitals and clinics that are ACoS certified would like to access the TCR to find out what else is being done on their patients once they leave their facility. This would help greatly in the patient follow-up information the facilities are required to report to the ACoS. One of the biggest reasons for wanting access to the TCR databases is to enable the hospital or clinic to perform adequate research on the patient so they can offer the best care possible.

Recommendation: There are several options for allowing reporters access to specific limited TCR information. A SandCrab application could be developed to allow access to the TCR. The implementation of such a system requires that rules be defined, based on confidentiality issues, for the specific type of information available to individuals connecting to the system. One option is to allow a reporter to see the data for cases they submitted themselves. This has the benefit of allowing the reporter to make corrections to their submission.

The TCR might consider allowing reporters to view information they did not enter themselves, but would be able to access in other ways, such as treatment, death, or geographic code information. Initial diagnosis and treatment information would be very useful to reporters since this could save them valuable time currently spent contacting and gathering information from those actually providing the particular service.

There are many confidentiality and political implications that the TCR needs to consider. All current state confidentiality and security issues need to be evaluated prior to implementation. If the TCR does decide to allow limited reporter access to the TCR data, the TCR needs to perform a requirements analysis, system design, system implementation plan, implementation, and testing to ensure the system properly enforces the rules for access to information. It should be noted that Louisiana Law provides follow up information on a patient to the original submitter only. The state did not want to inhibit a hospital from performing follow-up on a patient a reporter had submitted.

Reporters Unsure of Proper Cancer Reporting

Many reporters seemed to misunderstand some of the more unique reporting requirements. One reporter mentioned the hassle in reporting information on a patient who comes in for terminal or supportive care only. The hospital does not have a great deal of additional information on the patient and is not able to provide information for all of the TCR required fields. This reporter said she wished she could identify that the patient had only received terminal or supportive care, so the TCR would not call her back and ask why she had not reported any information for the additional TCR required fields. The reporter thought it would save her and the TCR time if she could inform the TCR up front that she had submitted all the information she had. The TCR staff confirmed that there is a "comment" field that reporters can use to identify that a patient has come in for terminal or supportive care only. A comment in this field notifies the TCR staff that the reporter does not have information for some of the TCR required fields, thereby avoiding a call to the reporter for the information.

Recommendation: Reporters need to be trained frequently on proper cancer reporting. While there are many unique cancer-reporting situations described in the TCR guidelines, some reporters are either not aware of these guidelines or may not recognize the application of a guideline to a specific case. Therefore, reporter education could result in saving valuable reporter time and TCR staff time. As mentioned above, the TCR staff confirmed that they currently spend a considerable amount of time training reporters. Due to the perpetual turnover in cancer reporting staff, the benefits of training are hard to retain. Facilities should be encouraged to identify a more stable position on their staff to receive the training.

The regional office should continue to conduct reporter training, once stable staff positions have been identified by the facility staff. Regional office staff could perform in-services and create "Frequently Asked Question" informational reports to be included on the TCR Web site. Reporters should also be encouraged to e-mail or call with questions they have about reporting. It may also be beneficial to contact each reporter facility occasionally to proactively resolve issues and questions.

Duplication of Effort When Facilities Submit Data for the Same Patient

In areas of shared hospitals and clinics, as in the healthcare system in San Antonio, a patient may go to Methodist hospital, South Texas Veterans hospital, or CTRC (a freestanding cancer clinic). These facilities are not technically affiliated, so they maintain their own cancer registry databases. However, when a patient goes to multiple facilities in the area, each of these facilities has to collect all of the patient

diagnosis and treatment information and submit it to the TCR and to ACoS. Therefore, they wish they had a local networked registry to reduce duplication of effort when multiple facilities provide services to the same patient.

Recommendation: The TCR should encourage and enable these reporters to set up some type of local networked registry. The TCR would benefit from a shared registry among multiple hospitals if the result was a reduction in duplicate submissions on the same patient. This type of registry could collect the data for all of the various facilities, store them in the networked registry, and submit them to the TCR on a regular basis via electronic format. The TCR could use the regional registry requirements used by California as an example to provide some guidance to the local networked registry developers. The Official California Code of Regulations implemented state statutes and has the same force of law as court decisions or legislation. The California Cancer Registry must comply with section 2593 of the Official California Code of Regulations, which is provided in Appendix F.

Reporters Discouraged That Submissions May Not be Processed in a Timely Manner

There were a few reporters who felt discouraged that their submissions were not being processed by the TCR in a timely manner. This was evident to reporters when they received letters from the TCR stating that they had not reported at least 50 percent of their cases for the year (by December). The reporters suspected that their recent submissions had not been processed by the TCR and thus it appeared as if they had not reported at least 50 percent of their cases when in fact they had. The reporters were frustrated they had to report to the TCR in such a short timeframe when the TCR was seemingly unable to process their submissions in a timely manner. One reporter said she called the TCR and confirmed with TCR staff that they had received and counted all of her submissions. The next month, however, she received a TCR letter that failed to list some of her submissions and informed her she was negligent in reporting less than 50 percent of her cancer patients. In addition, many reporters said they did not get called with questions about a submission until up to a year following their TCR submission. Reporters are left wondering why there is such a great demand on quick reporting when it appears their submissions are not processed in a timely manner.

Recommendation: A new software tool could be created to allow the electronic submission of reporter data. This tool would be available to reporters who submit data electronically by exporting data from commercial off-the shelf (COTS) tools or by generating files with SandCrab Lite. This solution is discussed in greater detail in Section 6-2. The advantage to this utility would be a reduction in the time it currently takes to process reporter information manually. The reporters' submissions would get processed immediately and incorporated into the TCR data consolidation process.

Many of the other recommendations mentioned in this document are geared at reducing the amount of time spent by the TCR staff in consolidating patient records. Therefore, the incorporation of these recommendations will allow the TCR staff more time to perform tasks that have to be done manually, thereby reducing overall time for reporter submission processing.

6.1.4 Reporters at Physician Offices

In the state of Texas, it is not currently mandated that physicians in physician offices report cancer information to the TCR; however, there are a few cancer cases that may only be identified in the physicians' offices. These include prostate cancer, breast cancer, melanoma, cervical cancer, and leukemia. The office infrastructure for these physicians is not currently set up for tracking detailed patient medical information. Most physician office computers are used for tracking patient name, SSN, and diagnosis. The patient address is often in a separate billing database. Many of the physicians' records only contain a portion of the TCR required data. Also, many physician offices have no hospital to which to report.

Issues Reported:

- **Insufficient Staff or Staff Knowledge**
- **Patients Submitted by Physicians May Already Exist in the Registry**
- **Concerns About Patient Confidentiality and Office Disruption**
- **Impression of Physicians That Their Own Participation is Not Important**

These issues and their recommended solutions are described below.

Insufficient Staff or Staff Knowledge

Many of the physician offices are staffed with physicians and administrative staff. The physicians do not have time to submit the cancer information and the administrative staff is not adequately trained to report cancer information. These physician offices lack the appropriate funds to hire staff familiar with proper cancer reporting.

The Baylor Medical Center in Dallas has been using a very successful methodology for gathering outpatient surgery and physician information. At Baylor, the outpatient surgery centers and physician offices send a listing of their diagnosis codes to a Baylor certified tumor registrar once a month. The certified tumor registrar then visits the outpatient surgery centers or physician offices and abstracts all of the relevant patient cancer information. The certified tumor registrars take a laptop on their visits and enter the necessary information in the registry software. This method has worked very well for Baylor and they have been able to gather the necessary patient cancer information without intruding on the office staff whom they visit.

Recommendation: The TDH and TCR stakeholders should encourage and enable large medical centers, clinics, and hospitals to abstract patient cancer information from their supporting physicians and outpatient surgery centers. In addition, the facilities could have the physicians e-mail their dictated notes.

It should be noted that large facilities may not have the resources to incorporate all of the physician information into their registry system. Therefore, this recommendation may require the large facilities to hire additional staff to incorporate the affiliated physician cancer information.

Once the state mandates physician reporting, the collection of this information will be easier since the larger facilities will have legal backing for their demands for physician cancer information. Also, then the larger facilities can offer to collect the information for the physicians and send it on to the TCR.

Another option would entail the incorporation of active regional participation similar to California's method for physician data collection (outlined on page 6-8). This process would require regional staff to go out and actively gather the physician information from the physician offices. It should be noted that the TCR might need to hire additional staff to incorporate active regional participation for data collection.

Lastly, a certified tumor registrar could be hired to gather cancer information from physician offices, as suggested for small, rural, and medium hospitals in sections 6.1.1 and 6.1.2. A number of physicians could pool together and hire a certified tumor registrar to gather their information. The TDH and its stakeholders may be able to work in tandem with all reporters to attract certified tumor registrars.

Patients Submitted by Physicians May Already Exist in the Registry

The TCR has been receiving oncologist patient lists from a practice management company, representing the nation's most extensive outpatient oncology network, to identify missing cancer patients and additional oncology information on patients already in SandCrab. A database of information available in the outpatient oncology network's billing system, including demographic (e.g., patient identifiers such as name, date of birth, social security number, address) and diagnosis and available treatment information (e.g., radiation therapy, chemotherapy, hormone, immunotherapy) on each patient, is compiled and sent electronically to the TCR. The TCR has been successfully using this information to identify missing cases and missing treatment for existing cases. Though this method has worked very effectively, it does require that TCR staff manually check to see if the patients already exist in SandCrab. The entire process is manually cumbersome for both the TCR and the oncology network. If all physician offices chose to use this methodology, it would create a great deal of additional work for the TCR staff.

In addition, the TCR is pilot testing a process with pathologists at a freestanding pathology lab in San Antonio. This pilot program, called the prostate cancer pilot, requires pathologists at the free-standing pathology lab to send lists of their cancer patients to the TCR. The TCR then uses the list of names as a casefinding mechanism to identify any cancer patients that are not in their SandCrab database. The TCR is then able to solicit the patient's physician for additional information on the patient.

It should be noted that new Texas legislation, effective in 2001, requires all reporters to report cancer cases within six months of diagnosis. If an amendment to require physician reporting passes in the legislature, they too will be required to report within the timeframe. Therefore, physicians and facilities would be sending in their cancer patient information to the TCR at the same time. This would negate the effectiveness of cancer patient casefinding, which is possible when physicians report much later than the facilities.

Recommendation: Given the impact of the new Texas legislation, it would be beneficial if the physicians could provide two separate submissions to the TCR. The physicians should send the TCR a list of all cancer patients as an export from their billing system, so the TCR could track all cancer patients seen in physician offices. In addition, the physicians need to devise a mechanism for identifying patients not previously admitted as inpatients or outpatients to a Texas cancer-reporting facility for primary care or patients that are referred by the physician to a hospital or cancer-reporting facility for diagnosis or treatment of cancer. The physicians could then electronically send in demographic, treatment and all other cancer related information on hand, such as referring provider, cancer stage, and cancer treatment, to the TCR. A SandCrab application could be designed to support the unique, physician-specific situation. This system would be a "SandCrab Lite for Physicians," created specifically for each type of physician. This software would only contain the fields that pertain to the given physician type.

It is possible that physician office staff may not have the time or skills for cancer reporting. In such instances, the physicians could hire a certified tumor registrar to perform their cancer reporting. On a monthly basis, the physicians could send a list of all patient disease indexes to the certified tumor registrar, who in turn could determine which patients were eligible for submission to the TCR. The certified tumor registrar could abstract the pertinent information from the physician office and submit the information to the TCR, on behalf of the physician, using the customized SandCrab Lite for the given type of physician.

As noted previously, it might be easier for a group of reporters to pool together and hire a certified tumor registrar to gather their information. The TDH and TCR stakeholders may be able to work in tandem with all reporters to attract certified tumor registrars. Reporter participation could also be solicited in a region to ensure that sufficient work existed to support a certified tumor registrar.

Concerns About Patient Confidentiality and Office Disruption

A few physicians preferred that an abstractor not come to their facilities due to concerns about patient confidentiality and the disruption of their office staff. These pathologists were willing to perform the staging and coding and then submit this information to their affiliated facility or the TCR.

Recommendation: All physicians willing to take the time to report to the TCR could provide information on a simplified FAX-back form at some interval in the diagnosis. This FAX-back form would have to be customized to the type of physician reporter providing the information. This could be started on a voluntary basis at Commission on Cancer-approved programs until legislation requiring physician submissions is enacted. The implementation of a FAX-back form may require additional staff at the regional offices for incorporating the data into the TCR

In addition, physicians who are a part of a larger medical center might opt for a local networked system that would support all the various physicians involved with a patient. In the larger medical facilities, a potential cancer patient record is first created by the surgeon who biopsies the patient specimen. A pathologist may enter information on a patient record created by a surgeon. The pathologist would not be entering all of the information until about 4–6 months later. This system could also

incorporate the oncologist, who could add the patient treatment information when appropriate. Implementing such a system could be accomplished by these groups joining to create a shared networked registry or by using an improved networked SandCrab Lite that would allow access to specific specialty fields for a fully identified patient. For example, a pathologist could only view and update the pathology-relevant fields in such a system.

Once again, the TCR could use the regional registry requirements used by California as an example to provide some guidance to the local registry developers. The Official California Code of Regulations implements the state statutes and has the same force of law as court decisions or legislation. The California Cancer Registry must comply with section 2593 of the Official California Code of Regulations, which is presented in Appendix F of this document.

Impression of Physicians That Their Own Participation is Not Important

One interesting observation was the perception by the physicians that the small amount of cancer patients they generate would not be useful to the TCR, since the TCR has information on so many more patients. The physicians are not as concerned about reporting to the TCR since they feel that their contribution would be irrelevant.

Oncologists felt it would be overly burdensome to report to the TCR since they would have to capture follow-up, changes in treatment, and when a patient dies, all of which they feel is already being reported by a hospital. Oncologists commented that there may be a great deal of duplication of effort since most cases are diagnosed in the hospital and the oncologist only adds treatment information. It is obvious that the oncologists are not aware of the importance of their participation in the registry to ensure complete and accurate cancer reporting.

There was also the opinion that the state needs to legally force the physicians to report. One physician said that the state needed to create a mandate and "put some teeth into it." One suggestion was to identify if the physician is tied to a hospital. The physician could be required to report to the hospital in order to retain admitting rights. One pathologist suggested that the state put out a clinical correlation form regarding physician reporting, so those physicians could only keep their privileges by reporting. Physicians felt that the TDH needs to develop protocol and a "blanket policy" on how reporting needs to be done in order to get physician involvement. There was consensus that a mandate and structured policy would enable the TCR to gather the necessary information from physicians.

Recommendation: Physicians need to be educated about the significance of complete cancer data to the TCR and proper cancer surveillance. The TCR should distribute memos outlining how CDC funding was lost due to a lack of complete data. One physician commented that the article in *Texas Medicine*, entitled "Reporting Cancer: TMA Group Improves the Cancer Registry,"[1] helped him grasp the importance of complete cancer reporting. It was the belief of this reporter that all physicians need to be made aware of the importance of reporting through the distribution of educational information to increase their desire to report. This

[1] Adams, Alice. (2000). Reporting Cancer: TMA Group Improves the Cancer Registry. *Texas Medicine*, 96:6:58-61.

information could be included in the *Texas Cancer Reporting News* newsletter and also be conveyed by the regional staff during their solicitations for data from physicians.

Until the physicians are legally obligated to report to the TCR, it will be hard to motivate them to report. Once physician involvement is mandated, the TDH needs to perform a requirements analysis to determine what data are needed from the various reporters and how they can be easily obtained.

6.1.5 Reporters Who Are SandCrab Lite Users

Issues Reported:

- **Limitations of SandCrab Lite**
- **Multiple Versions of SandCrab Lite in Use**

These issues and their recommended solutions are described below.

Limitations of SandCrab Lite

SandCrab Lite is the reporting software developed and distributed by the TCR free of charge. Users of SandCrab Lite mentioned a need for:

- the functionality to import patient demographic information from their current patient/billing/medical system;
- the ability to use SandCrab Lite as a networked system to avoid duplicates;
- access to various "canned" reports, like productivity by hospital and hospital incidence; and
- the ability to gather multi-facility information.

Recommendation: The TCR could incorporate these changes where funding and resources allow. There are reporters who indicated dissatisfaction with SandCrab Lite software and are looking at off-the-shelf products to report to the TCR. The central office staff, who spend time troubleshooting why submissions do not pass the NAACCR edits as part of their data processing, mentioned that the SandCrab Lite software submissions pass all of the NAACCR edits. Therefore, it would be beneficial for the TCR to improve SandCrab Lite and increase utility among reporters, thereby decreasing the time central office staff must spend on submissions that don't pass the NAACCR edits. Although reporters using other registry systems would likely be expected to continue using their own software according to internal facility procedures, there are opportunities for attracting new reporters as they join the process.

One option would be to create a new and improved SandCrab Lite for Windows with the capability to be networked within an office so that several reporters could simultaneously update a multi-user database. In this manner, reporters could work on a shared system that would minimize the risk of duplicates. This SandCrab Lite could also incorporate Windows standards or the best features that Windows environments have to offer. This new SandCrab Lite could also have the capability

to connect to the TCR and provide reporters with electronic transfer and loading of cancer data directly to the TCR. This utility would allow reporters to access only their data and generate reports accordingly.

Other recommended improvements to the current SandCrab Lite include:

1. Incorporation of a smarter, more user-centered interface that better assists even less experienced reporters in entering correct cancer data. The screens should follow Windows standards. The application could have more rules to resolve conflicts and reduce errors in reporting.

2. Addition of a feature that allows the import of patient billing record demographic information directly into the software to reduce reporter data entry.

3. Use of the *Cancer Reporting Handbook*[2] to augment the application in several ways:

    a. The tool could help the reporter fill in data by automatically selecting codes or offering an appropriate subset. The tool could catch simple errors based on information loaded from the handbook. For example, based on a patient's Hispanic surname, the software could remind the user that the Hispanic code should be selected. The handbook's list of Spanish/Hispanic surnames could be part of the tool's validation database.

    b. The tool could offer internal "calculators" or help buttons to look up items such as the tumor size conversion chart. For example, if the user types or selects "almond," the field would automatically fill in the correct size of 30mm.

    c. The tool could allow the reporter to search for information with "on-line" help (instead of manually searching through the handbook). There are several ways the manual could be available from the tool to allow quick searches by a topic or keyword the user specifies.

4. Ability to offer and encourage users to submit questions to the TCR office electronically, with questions about the tool and questions on how to report cancer cases properly. If the user does not have e-mail from other sources, the tool can offer TCR electronic messaging directly to TCR staff.

5. Incorporation of the NAACCR Edits Application Program Interface (API) to validate data.

6. Employment of new features that allow users to connect to the registry to view and correct their own submissions only. This feature will require

[2] *Texas Cancer Registry Cancer Reporting Handbook*, Texas Department of Health, April 2000.

the evaluation of all current state confidentiality and security issues prior to implementation.

The development of the new SandCrab Lite should be initiated with a thorough requirements analysis that incorporates input from current users of the software, as well as certified tumor registrars who understand proper cancer reporting. The next step would involve system development, implementation, and some type of pilot testing period to incorporate user input and suggestions. Once the software has been tested and is ready for release, reporters could be trained during regional office in-services. The TCR could increase exposure among the reporter community by previewing the software to all reporters. This type of exposure would benefit the TCR.

Multiple Versions of SandCrab Lite in Use

One abstractor who visits various hospitals to abstract cancer patient information mentioned that many hospitals have different versions of the SandCrab Lite system. This abstractor suspected that the hospitals were not upgrading the software as upgrades became available. Also, it appears that some reporters have forgotten to upgrade from SandCrab Lite DOS to SandCrab Lite Windows as they acquired new technology in their technical infrastructure. The unfortunate outcome is more work for abstractors who have to accommodate hospitals with differing systems. This also becomes an issue for the TCR when the CDC releases new versions of the NAACCR format and users are not running the most current SandCrab Lite system that incorporates these requirements.

Recommendation: Besides increasing the communication and training to make sure people are using the latest version of SandCrab Lite, there is an automated solution if a version of SandCrab Lite that connects to the TCR were developed. As described in the previous section, this new SandCrab Lite would connect to the TCR to allow submission of the SCL data or to view reports. This system could incorporate a version check so that if the user has an old version of SandCrab Lite, the user would be prompted to upgrade and immediately download the new version. There could be required upgrades versus recommended upgrades, depending on whether the newer version actually affects the data or just has enhancements to the interface.

6.2 Focus Group Category: IM/IT Personnel

The IM/IT personnel represent all those systems and technical staff involved with TCR reporting, data compilation, and the data output process. As mentioned above, VRI met with the TCR IM/IT personnel to understand their process for compiling reporter information and generating reports. During this session many issues were raised with the current process from the perspective of the reporters, the regional office, and the central office.

Issues Reported:

- **TCR Burdened by Continuous Changes to Cancer Reporting Requirements**

- **Central Office Processing Burdened by Incomplete or Incorrect Submissions**
- **Central Office Wastes Time Handling Duplicate Submissions**
- **Central Office Consolidating Multiple Patient Records by Hand is Burdensome**
- **Central Office Obstacles to Geo-Coding Patient Address Information**
- **Central Office Difficulties Incorporating Corrections in a Timely Manner**
- **Transmission Line Traffic Slows Regional Offices Using SandCrab On-Line**
- **Regional Offices Do Not Have Access to All SandCrab Functionality**
- **Limitations of Current SandCrab and SandCrab Lite for Expanded Use**

These issues and their recommended solutions are described below.

TCR Burdened by Continuous Changes to Cancer Reporting Requirements

As mentioned in Section 2.3, a registry must be able to collect additional data variables, modify coding schemes, and revise reporting formats in keeping with refinements to reporting standards set by the NAACCR. Other evolving standards affecting data interpretation include changes in the year 2000 standard population used for data analysis and changes in the diagnosis coding scheme for mortality data. Trying to respond to all of these changes takes many man hours and requires training to understand implications, incorporate change, and convey this information to the reporters. According to TCR staff, these and other factors affect the TCR's ability to analyze and produce timely reports.

Recommendation: The TCR may need to work with the national standard setting organizations to limit the frequency of and magnitude of changes. Also, the TCR needs to stress to these organizations the need for adequate advance notice and documentation. By providing this type of feedback to the national standard setting organizations, the TCR may be able to minimize the negative impact these actions have on their current workload.

Central Office Processing Burdened by Incomplete or Incorrect Submissions

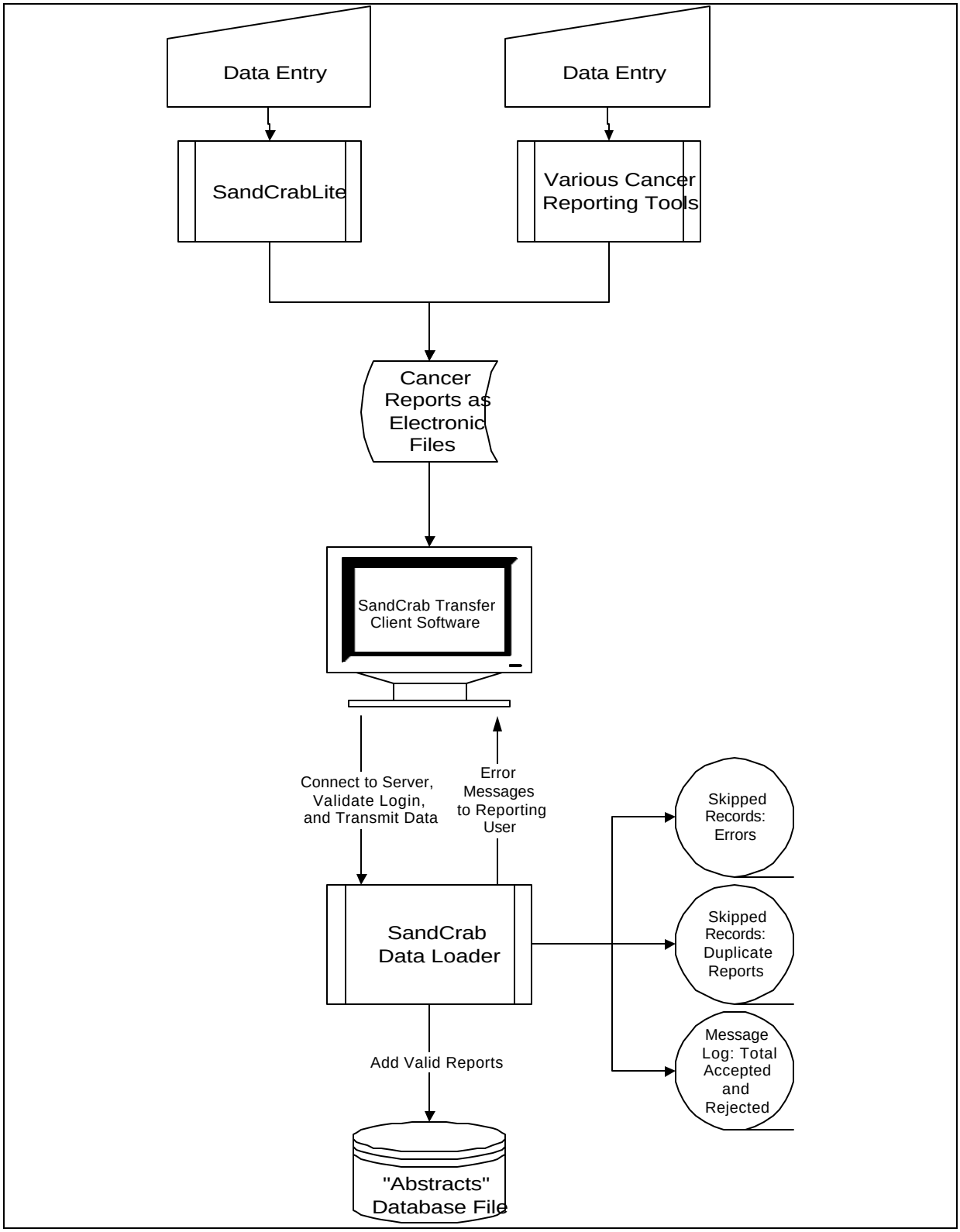
Reporters often submit blank, incomplete, or unreadable electronic files to the central office. The central office spends a great deal of time trying to process these submissions, only to find they must contact the reporters and tell them to re-send their submission. A number of the non-SandCrab Lite electronic submissions do not pass the minimum NAACCR requirements for data quality. Reporters also often send duplicate submissions. All of these activities burden the central office staff members who are trying to process all of the submissions and make the patient information pass through the SandCrab edits.

Recommendation: A new software tool could be created to allow the electronic submission of reporter data. This tool would be available to reporters who submit data electronically by exporting data from commercial off-the-shelf (COTS) tools or by generating files with SandCrab Lite. The application would connect to a TCR

server and allow immediate encrypted transmission of a data file to the registry. The user would receive information on the rejection of invalid data, including a log with errors, counts of successfully transmitted records, counts of duplicate records, and counts of failed records. The tool could be a separate piece of software called the Sand Crab Transfer Tool, or the functionality could be rolled into a new version of SandCrab Lite. See Exhibit 6-1 for a depiction of this process.

In addition, the tool could include the ability to generate reports on cases the user has submitted (e.g., counts, a list of names, or whatever is useful and appropriate). As this method of submission becomes more and more popular, the current FoxPro SandCrab system will quickly reach a point where it is unable to handle the increased number of users. In this case, a transition to another system better suited for multi-user access would be recommended.

Exhibit 6-1: Proposed SandCrab Transfer Client



Central Office Wastes Time Handling Duplicate Submissions

The central office spends a considerable amount of time trying to read in files that are duplicate submissions from the reporters.

Recommendation: Sending duplicate records is a common occurrence in automated systems with electronic submissions and should not be a burden on the central office staff. An automated system can easily identify a duplicate and skip the duplicate records. The SandCrab system should have a data loader that generates a report of the bad record count, duplicate record count, and valid record count so that the reporter is aware of what they have sent, in case they inadvertently sent an older file. The Transfer Client discussed previously in this document would make use of this loader on the server to inform the reporter directly. If duplicate records are encountered within a submission, the tool could be programmed to either accept a portion of the submission or reject the entire submission.

Central Office Consolidating Multiple Patient Records by Hand Is Burdensome

The central office invests a great deal of time consolidating multiple patient records. This process is currently manual and requires quite a few steps to ensure no additional information is lost during the process. The central office staff made a list of the steps that can be automated, along with the steps required in automating the step. Due to a lack of resources, these recommendations have not been incorporated. The suggestions made can be grouped into the following categories:

1. Automate consolidation of primary sites that meet the guidelines for being one primary site.
2. Automate the process for a valid date overriding "unknown date" or "unknown code" or "invalid code."
3. Automate the process for sequencing numbers on multiple primaries based on diagnosis date.
4. Automate the laterality to determine multiple primaries.
5. Assign grade and stage per guidelines.

Recommendation: Due to the amount of time spent on this process, it is recommended that some of these suggestions be incorporated as quickly as possible.

Central Office Obstacles to Geo-Coding Patient Address Information

Another problem facing the central office staff is geo-coding patient address information. Many patients provide "PO Box" addresses to their doctors for billing purposes; therefore, the TCR staff is unable to determine the place of residence of the patient. Relying on place of service is not always an accurate indicator of incidence, since many patients (especially in the Hill Country) go to other counties for their healthcare services due to the availability of better care.

Recommendation: The TCR needs to incorporate rules and regulations for patient street address consistency and have the SandCrab Lite software enforce them. Users of other systems may need to be educated and a process — whether manual or automated — may require implementation to clean up other addresses.

Central Office Difficulties Incorporating Corrections in a Timely Manner

The central office also receives corrections from their reporters for previous submissions. The reporters who capture their cancer information electronically tend to send the corrections on a disk to the central office. Central office staff members have been unable to incorporate the corrections in a timely manner due to the enormous amount of work they currently perform.

Recommendation: The most accurate way to incorporate corrections would be to allow reporters to view and correct their own records on-line. However, current privacy and confidentiality restrictions might limit non-TCR access to the SandCrab system. Therefore, an alternative option would involve allowing reporters to submit errors via the Sand Crab Transfer Tool mentioned above or the new SandCrab Lite connected to the TCR. These corrections would then be incorporated into the new automated consolidation process where the TCR staff would process them accordingly.

Transmission Line Traffic Slows Regional Offices Using SandCrab On-Line

As mentioned above, the regional office connects to the SandCrab system via on-line access to perform data entry, data editing, and error resolution. The response time from the host computer in the central office to the regions is slow due to the heavy traffic on the transmission lines. This slowdown is caused not only by the significant network traffic generated by the regional staff using the SandCrab client, but also by the multiple state agencies that use these same lines. When the regional office staff members try to use SandCrab from their site, they end up wasting a considerable amount of time on system response. The result is that the regional staff will sometimes enter hospital data into SandCrab Lite and send it to the central office, rather then taking the extra time to enter data directly into SandCrab. The regional office staff must do data editing and error resolution, so regional staff members have no other choice but to use SandCrab in these instances. In addition, the central office often runs reports for the regional office staff since it takes so long to do this at the regional level.

Recommendation: The TCR could develop an improved Regional SandCrab client application to access the main TCR server. This new version could be designed to reduce network traffic and thus increase the perceived speed to allow regional staff members to more efficiently access all the data they need. The improved application would transfer data in larger pieces so that the regional staff can complete changes for at least one case at a time before requiring communication with the server. Improvements would also include local duplicate tables for certain types of supporting data that can be updated at connect time if they have changed.

Regional Offices Do Not Have Access to All SandCrab Functionality

There also seems to be some duplication of effort between regional and central office staff. The regional office staff is not able to create mailing labels and must have the central office run these labels for them. Alternatively, the regional office staff can keep the facility information, such as contact names and addresses, in a separate spreadsheet so that they can generate their own labels from the spreadsheet.

Recommendation: The SandCrab system needs to make all functions available to the regional offices so they can best perform their job. The improved Regional SandCrab client application could allow regional staff to use the contact and address information without having to maintain separate spreadsheets of the same information. Regional staff members should help define which special features need to be incorporated to assist them, such as the ability to generate labels, automated e-mails, or form letters to reporters, if they believe it would save them time. This discussion with the regional office staff may also generate ideas for regional office specific tasks that the Regional SandCrab client application could incorporate.

It should be noted that the central office staff confirmed that they have written programs that would enable regional office access to all features available at the central office. However, the code has not been tested and implemented due to a lack of data management staff and resources.

Limitations of Current SandCrab and SC Lite for Expanded Use

The current SandCrab system was designed and developed by the TCR staff in response to the need for a statewide registry. The system was originally developed in FoxPro 2.0 and more recent upgrades have been done in Visual FoxPro 6. The TCR staff has incorporated the procedures necessary to support its operations; however, the tool still requires a great deal of manual work. In addition, there are potential limitations with FoxPro database tables. Although the TCR office has been able to avoid the table size limits thus far by moving older data to archive tables, there is a point well below the maximum where moving the data to Oracle or SQL Server becomes indicated.

Having the capacity to store larger amounts of data together, such as by data warehousing, would allow for more analysis and observation of trends. Older file server-based applications written in Visual FoxPro can reach limits in the number of simultaneous users, due to the high network traffic that results from this kind of architecture, where the processing occurs on client machines. Some of this can be improved by incorporating true client-server applications.

As shown in the Appendix A diagram for the current system, there are several operations external to SandCrab that require manual intervention in initiating and completing the processes. These operations could be better incorporated into the system and include operations such as automatch for de-duplication, the geo-coding process, the validation with NAACCR edits, and the death matches with data provided by the Bureau of Vital Statistics.

SandCrab Lite is the reporting software developed and distributed by the TCR free of charge. This application was initially developed to support users with machines running DOS and eventually an additional version was generated to support Windows users. This interface was not really designed for Windows so it does not fully incorporate Windows standards or the best features that Windows environments have to offer. As described in Section 6.1.5, SandCrab Lite users could benefit from several additional features.

Recommendation: In the long term, the SandCrab system will have difficulty incorporating new functionality, storing larger amounts of data, and allowing more

users to access the system due to FoxPro limitations. The TCR should consider re-designing and developing an updated SandCrab that fully incorporates all system requirements and uses a more powerful database that makes the system scalable, allows keeping up with technology such as the Web, and can more easily grow and evolve.

This new system would allow the possibility of a distributed registry among regions if desired, automate all operations where possible, include the use of existing tools such as NAACCR Edits, and include automatic geo-coding, when appropriate. It could be set up to run duplicate checking or other utilities on a scheduled basis. It would be designed to be scalable so that the system could grow over time, including a larger number of users, larger amount of data, and more reporting and analytical processing. The new system would allow for the storage of all historical and current data together to facilitate analysis. This could be implemented as a data warehouse to support more analysis, data mining, and reporting. In addition to using the tools now available to the TCR, new tools in the market today help identify trends in large amounts of data, which may have a practical application in epidemiological studies. Having a new system would of course require proper planning to transition from the first SandCrab to the new one.

Initially this task would involve performing a systems requirements analysis to assess the needs of the central and regional office staff. The next step would be a system design, implementation plan, implementation, testing, documentation, and training. The implementation plan should include timelines for identifying and incorporating various database and connectivity requirements. The system should be designed and coded using object-oriented techniques. This will facilitate future updates to support changes that will come from the addition of new technology and new requirements by the CDC or the Health Insurance and Portability and Accountability Act (HIPAA).

6.3 Focus Group Category: End Users

An end user is defined as any person who uses the TCR data for research, patient care, or other type of healthcare decision-making. For this study, VRI received input from reporters, public health researchers, academic researchers, and physicians. Many of the comments raised by end users had to do with access to data, the timeliness of data, and suggestions for specific reports.

Issues Reported:

- **Poor Timeliness of Data**
- **TCR Reports Need Enhancements**
- **End Users Need More Local Support**
- **Difficulty Accessing Detailed Data**

These issues and their recommended solutions are described below.

Poor Timeliness of Data

The biggest concern end users voiced was regarding the timeliness of the information the TCR compiles in their annual reports. A number of end users also said they did not use the data because the data were so old. Other reporters said that they manipulated SEER data for California to get a more current view of the incidence in Texas. The end users mentioned that the timely availability of cancer data would help them with funding cancer control initiatives and the creation of cancer-related policy decisions.

Recommendation: Many recommendations have already been proposed in this document to increase the efficiency of the TCR process. The TDH and TCR stakeholders need to determine which recommendations will be implemented. Immediate improvements in efficiency will be seen when the central office has some automated steps in the patient consolidation process, the regional office staff is able to do its work directly on SandCrab with faster access, and the submission and loading of electronic data is done by the reporters themselves.

TCR Reports Need Enhancements

End users reported many specific concerns about the data in reports or the way the data were presented. These concerns are listed below.

Insufficient Data in Reports

- Some epidemiologists felt they were not getting enough detail in the TCR reports for the type of research they perform. One area mentioned quite often was the lack of population-based data (e.g., number of patients by hospital) for population-based research. Also, end users need to know which hospitals have the largest number of cancer cases so they know where to target their cancer analysis. It should be noted that the TCR staff clarified that all data published by the TCR are population-based, not hospital-based. Facility-specific reports with caseloads can be requested, though the TCR cannot release a specified facility's identity unless required by law. The TCR will contact a specific facility and request their permission to release their facility's non-personal identifying information. Therefore, this may represent a training opportunity to clarify to end users the type of data they can receive and steps to be taken to collect additional information.
- Some end users admitted they would get much better funding for their grants if they had better supporting data from the TCR. Included in this is the lack of population-based information in the annual reports.
- Many end users mentioned the need for geo-coded incidence information for performing their epidemiological research.
- An end user in the Hill Country asked if the reports could be run by patient address rather than the location of service. Apparently, patients in Mason County come to Gillespie for cancer services; therefore, the TCR public health regions that rely on location of service do not represent the true incidence in the Hill Country. It should be noted that the TCR staff verified that reports are created by county of residence; therefore, this issue may represent a need for clarification on how data are being displayed.

- End users wish that there were more pathologist involvement for the blood sample studies they do.
- Some epidemiologists mentioned that their studies required the pathology lab information prior to the patient receiving treatment.

Enhancements to TCR Web Site

- Some end users and reporters were hoping for the availability of cancer incidence, mortality, and staging data available by county in a user-friendly format on-line.
- End users wish that all of the TCR reports were Web-based for easy access.
- Some end users were hoping to get the annual reports on-line in PDF format with combined incidence and mortality information on one document.
- Some end users were hoping for links on the TCR Web site to other relevant information like population statistics and demographic information.
- End users wished that the TCR had descriptive slides and graphs available on the Web site.
- As mentioned above, the researchers were hoping that the TCR would put together reports on the Web site enumerating all of the research that had been generated from the TCR data. They thought that this would give other researchers ideas for potential studies.

Recommendation: The TCR needs to weigh the costs and benefits of these requests and incorporate enhancements accordingly. The inclusion of the reports requested from the end users would serve as a good marketing opportunity to demonstrate the usefulness of collecting quality cancer information throughout Texas.

It is important to recognize that various tools and entities available in Texas represent many uses of many different cancer data sets in various contexts as information is developed and used for specifically targeted prevention and control efforts. Because of this, there is a need to integrate and make available — in one location — a state's comprehensive cancer information including morbidity, mortality, risk factor information, population demographics, provider and hospital information, patient resources, and other data. In other words, the state should provide a point for one-stop shopping for all published and disseminated forms of cancer data as well as users of cancer data in prevention and control efforts. Ultimately, a central Web site should be created to serve as a central point of contact for all published and disseminated forms of cancer data and those entities that use cancer data in cancer prevention and control efforts. The TCR Web site could be enhanced to become this site, or another Web site could be created or enhanced to become the cancer gateway and provide a link to the TCR Web site.

End Users Need More Local Support

Some end users wished for more cancer reporting experts at the regional office level so that researchers could have more local access to TCR staff for help. Researchers felt that this type of access would only benefit the utility of the TCR data for cancer surveillance.

Recommendation: It has been already mentioned that the Lubbock regional staff involvement with reporters has gained reporter trust and cooperation. In addition, researchers need access to staff members at the registry to whom they can direct their questions regarding any analysis they may wish to undertake using the registry data. The State of Texas needs to invest staff and funding into leveraging the full utility of regional staff involvement with the community.

Difficulty Accessing Detailed Data

Researchers felt they needed an easier way to access the TCR data. There was some frustration that due to confidentiality restrictions, the researchers were not deriving the full anticipated benefit from the TCR. Many end users said the process for accessing detailed-level data valuable to their research was cumbersome and sometimes unsuccessful. All researchers requesting personally identifiable information from the TCR must submit a request for approval through the TDH Personal Release Data committee. The committee makes the final decision on which researchers will be granted access to which portions of the TCR data.

A few end users commented that if the TDH decided to change their policy on accessing data, it should be equitable to all researchers, with the terms and conditions applied to everyone.

Recommendation: It seems evident that easier access to some of the types of information will increase the credibility and usability of the TCR. If the TDH decides to allow researchers access to TCR data, this can be limited to selected fields or summarized information on reports. These reports could be included on the TCR Web site and secured via password protection. The main issue is to define a set of rules for what information should be allowed for each type of user. A well-designed system should give users and reporters confidence that security and confidentiality is being properly handled. Current technology supports the secured sharing of data and limiting data access based on pre-defined rules. The implementation of this type of feature will require the evaluation of all current state confidentiality and security issues prior to implementation.

In addition, the TCR should consider incorporating some of the current cancer reports as public use data files on the TCR Web site, with consent agreements for appropriate use. In this manner, cancer data will be readily available to the cancer research community.

6.4 Focus Group Category: Government Officials/ Funders/Regulators

Issues Found:

- **Health Insurance Portability and Accountability Act Regulations**
- **Pending State Legislation Regarding Privacy**

These issues are described below.

Health Insurance Portability and Accountability Act Regulations

The Health Insurance Portability and Accountability Act (HIPAA) of 1996 was designed to protect health insurance coverage for workers and their families when they change or lose their jobs. The Administrative Simplification (AS) provisions part of HIPAA was added on at the request of the healthcare industry. The AS was created to reduce costs and administrative burdens of healthcare by making possible the standardized, electronic transmission of many administrative and financial transactions that are currently carried out manually on paper. The Department of Health and Human Services (DHHS) is planning to issue HIPAA AS Regulations in the areas of:

1. Transactions and Code Sets (Final published on August 17, 2000; compliance expected by October 16, 2002).
2. Identifiers (Employers, Providers, Health Plans, and Patients).
3. Security.
4. Privacy (Final published on December 28, 2000; compliance expected by February 26, 2003).

The regulations for standardized transactions, code sets, and identifiers apply primarily to providers, health plans, and government agencies acting in these roles. There are specific formats defined for eight mandated transactions, and supporting codes for diagnosis, procedures, etc. The mandated transactions are:

1. Health claims and equivalent encounter information.
2. Enrollment and disenrollment in a health plan.
3. Eligibility for a health plan.
4. Healthcare payment and remittance advice.
5. Health plan premium payments.
6. Health claim status.
7. Referral certification and authorization.
8. Coordination of benefits

All private sector health plans (including managed care organizations and ERISA plans, but excluding certain small self-administered health plans) and government health plans (including Medicare, state Medicaid programs, the Military Health System for active duty and civilian personnel, the Veterans Health Administration, and Indian Health Service programs), all healthcare clearinghouses, and all healthcare providers that choose to submit or receive these transactions electronically are required to use these standards. These "covered entities" must use the standards when conducting any of the defined transactions covered under the HIPAA.

Through these regulations, HIPAA is intended to encourage electronic data transfer and standardize electronic data interchange (EDI) formats. This in turn will have a positive impact on the data collection process as reporters streamline their data store process. The standardized data interchange regulations will enable the TCR to gather electronic information easier. With the onset of electronic medical records, reporters will be able to share their patient diagnosis and healthcare information in a structured pre-defined manner. This in turn will enable the TCR to gather the data affected by these regulations in a timely manner. Exporting electronically stored data into pre-defined cancer registry fields will benefit reporters and the TCR in timesavings and accuracy.

The Security and Privacy Regulations apply to all individually identifiable health information in electronic and paper form and to all organizations that collect, store, or transmit such information. In addition to providers and health plans, the regulations apply to government agencies, employers, service bureaus, contractors, and other entities. All clinical and business functions are affected, including disease management, utilization review, organ donations, disease registries, communicable disease monitoring, pharmacy, lab, radiology, data warehousing, Web sites, Intranets, etc. The regulations codify traditional ethics and sound business practices. The regulations require the creation of administrative policies (such as consent and authorization forms for patients) and continuous monitoring. The regulations do not require specific technologies. Primary enforcement will be through accreditation organizations (e.g., JCAHO, NCQA). The regulations create an expectation of "best practice" that the public (or the courts) may apply to all organizations.

Through the regulation there will be accountability of those who receive or store information. There will be boundaries and limits on data disclosure and usage. There will be a requirement to incorporate security against inadvertent use or disclosure.

Pending State Legislation Regarding Privacy

In addition to the privacy regulations outlined by HIPAA above, Texas is working to implement state law governing the privacy of medical information. This legislation is currently pending approval.

Recommendation: The current framework of the TCR does not allow for patient identifiable information to be shared with anybody outside of the TCR structure without appropriate approval and as allowed by law. Patient confidentiality has been guarded very carefully and it is very difficult for reporters, researchers, and end users to easily get confidential information. However, the TDH needs to perform a requirements analysis to assess the requirements of the HIPAA Privacy Regulations and the pending state legislation to determine their impact on the registry. The TCR will need to assess the implications of the final regulations, and assess the current TCR infrastructure and the process used for data sharing. All procedures and policies that tie to the regulations will then need to be assessed for modifications.

Within the HIPAA privacy regulations, an entity, such as a registry system, may use or disclose protected health information to the extent that such use or disclosure is required by law and the use or disclosure complies with and is limited to the relevant requirements of such law. Since the Texas law requires cancer reporting, the TCR would be exempt from requiring written consent or authorization for use or disclosure of the patient cancer information. Reporters are exempt from the privacy regulations regarding their reporting to the TCR. The TDH and the Personal Release Data Committee should work with the reporters to ensure that they understand the HIPAA final regulations and any implications identified by the pending state legislation. In addition, the needs of reporters and end users should be reevaluated against the new restrictions to identify opportunities for data sharing within the new constraints.

6.5 Focus Group Category: Professional Constituent Groups

A professional constituent is defined as someone who through his or her professional involvement is concerned with the success of the TCR. VRI received information from a member of the American Cancer Society, a member of the Texas Society of Pathologists, and the president of the Texas Society of Medical Oncology.

Issues Reported:

- **Poor Timeliness of Data**
- **Reporters and End Users Need More Local Support**
- **Impression of Physicians That Their Own Participation is Not Important**

These issues and their recommended solutions are summarized below.

Poor Timeliness of Data

There was a feeling that the TCR data need to be more current to be of better use to end users and reporters. The professional constituents felt that cancer information made available in a timelier manner would increase the utility of the cancer registry and its impact on cancer surveillance.

Recommendation: Many recommendations have been mentioned above that would increase the efficiency of the TCR process. Once again, the TDH and TCR stakeholders need to determine which recommendations will be implemented. Immediate improvements in efficiency will be seen when the central office has some automated steps in the patient consolidation process, the regional office staff is able to do its work directly on SandCrab with faster access, and the submission and loading of electronic data is done by the reporters themselves.

Reporters and End Users Need More Local Support

The professional constituents also wished the regional offices were better equipped to respond to reporter and end user needs. They felt cancer researchers need access to local staff to aid in understanding the uses of the cancer registry data and reporters need local support for questions and issues. It was felt that the regional offices should serve as a resource to the community in cancer reporting.

Recommendation: The entire cancer community will benefit with increased access to local staff members who can provide guidance and support with the TCR efforts. Reporters and end users have spoken to the benefits of regional staff involvement. An investment needs to be made for staff and funding, to leverage the full utility of regional staff member involvement with the community.

Impression of Physicians That Their Own Participation is Not Important

There is a feeling that if the physician does not have a significant amount of cancer cases to report, the data will not be useful to the TCR or make a big difference to the total amount of cases reported. This creates a potential for missing cancer cases that

do not come to hospitals, since many physicians, pathologists, urologists, and others do not feel motivated to report and many of the initial diagnoses of cancer are made in the outpatient centers, ambulatory centers, and physician offices.

The following were offered as suggestions for improvement:

1. Target non-reporters.
2. Emphasize the need for reporting biopsy cases, because they can start getting put in the registry and TCR can start looking for them when they get diagnosed in a couple of months. This would include education on identifying the patient from the initial diagnosis.
3. Distribute more articles and information to reporters to motivate them to report and feel involved with the registry. The article in *Texas Medicine* titled "Reporting Cancer: TMA Group Improves the Cancer Registry" would help physicians understand the importance of a complete cancer database.
4. Provide more Frequently Asked Question (FAQ) types of information to reporters.

Recommendation: It would be beneficial to have the regional registries educate reporters on the significance of their data submission. They can stress that the TCR lost CDC funding due to incomplete data, therefore, all data are relevant and important. There also needs to be education conducted on how to identify a cancer patient from the initial diagnosis and the TCR needs to emphasize the need for reporting biopsy cases in order to perform their cancer patient case finding efforts.

Exhibit 6-2: Matrix of Issues by Reporting Group

Reported Issue	Reporters	IM/IT Personnel	End Users	Gov Officials/ Funders/ Regulators	Professional Constituent Groups
Participation Seen as a Burden/ Reporters Apathetic About Reporting	√				
Insufficient Staff or Staff Knowledge (or Technology)	√				
Lack of Electronic Linkages to Different Sources of Data	√				
Reporters Want to See TCR Data on Their Patients	√				

Reported Issue	Reporters	IM/IT Personnel	End Users	Gov Officials/ Funders/ Regulators	Professional Constituent Groups
Reporters Unsure of Proper Cancer Reporting	√				
Reporters and End Users Need More Local Support			√		√
Duplication of Effort When Facilities Submit Data for the Same Patient	√				
Reporters Discouraged That Submissions May Not be Processed in a Timely Manner	√				
Patients Submitted by Physicians May Already Exist in the Registry	√				
Concerns About Patient Confidentiality and Office Disruption	√				
Impression of Physicians That Their Own Participation is Not Important	√				√
Limitations of SandCrab Lite	√				
Multiple Versions of SandCrab Lite in Use	√				
TCR Burdened by Continuous Changes to Cancer Reporting Requirements		√			
Central Office Processing Burdened by Incomplete or Incorrect Submissions		√			
Central Office Wastes Time Handling Duplicate Submissions		√			
Central Office Consolidating Multiple Patient Records by Hand is Burdensome		√			
Central Office Obstacles to Geo-Coding Patient Address Information		√			
Central Office Difficulties Incorporating Corrections in a Timely Manner		√			
Transmission Line Traffic Slows Regional Offices Using SandCrab On-Line		√			
Regional Offices Do Not Have Access to All SandCrab Functionality		√			
Limitations of Current SandCrab and SandCrab Lite for Expanded Use		√			
Poor Timeliness of Data			√		√

Reported Issue	Reporters	IM/IT Personnel	End Users	Gov Officials/ Funders/ Regulators	Professional Constituent Groups
TCR Reports Need Enhancements			√		
Difficulty Accessing Detailed Data			√		
Health Insurance and Portability and Accountability Act Regulations				√	
Pending State Legislation Regarding Privacy				√	

7.0 Assessing the Feasibility of Multiple Database Regional Registries

There has been much discussion regarding the feasibility of multiple database regional registries in Texas similar to those in California and Louisiana. Prior to any recommendations, it is important to understand the functionality of the multiple database regional registries in these states and consider the impact this would have on the current TCR infrastructure.

It should be noted that a multiple database regional registry is encompassed of separate non-networked registry databases in each region. Regional registry staff members do not have access to each other's databases or the statewide combined database.

7.1 The California Cancer Registry Model

The California Cancer Registry (CCR) is California's statewide population-based cancer surveillance system and is operated by the California Department of Health Services in collaboration with the Public Health Institute and ten regional cancer registries. It should be noted that three metropolitan areas in California participate in the Surveillance, Epidemiology, and End Results (SEER) program.

The SEER program is a population-based system of registries funded by the National Cancer Institute (NCI). It is an outgrowth of the National Cancer Act of 1971, which included a mandate to collect, analyze, and disseminate data that would aid in the prevention, diagnosis, and treatment of cancer. SEER was established to provide continuous cancer registration coverage in certain U.S. regions. SEER routinely generates national estimates of cancer incidence for most cancer sites from a non-random, national sample for all races combined (i.e., blacks and whites) and by gender. These activities are accomplished through a contractual arrangement with non-profit organizations to collect and transmit data for all new cases in their geographic locations. The metropolitan areas within California are Los Angeles, San Francisco/Oakland, and San Jose/Monterey. All metropolitan areas of SEER are also covered by NPCR-funded states. Incidence, survival, and treatment data are obtained through the contract mechanism with medically-oriented, non-profit organizations empowered by the laws and/or support from the cancer community in states covered by the SEER program, which include a SEER area to collect confidential information on persons diagnosed with cancer. The CCR is funded by the state of California. The SEER metropolitan agencies also get funding from NCI.

The California Health and Safety Code, Section 103885 requires hospitals, physicians, and certain other healthcare providers to report all new diagnoses of cancer. All facilities defined as cancer-reporting facilities must provide the complete cancer information to the regional registry. Physicians, dentists, podiatrists, other practitioners, and facilities not already defined as cancer-reporting facilities must report diagnoses in those patients who do not undergo diagnostic procedures or treatment of their malignancies at a hospital or other cancer-reporting facility in California. The multiple regional cancer registries, operating under the authority of

the Department of Health Service's California Cancer Registry, have the responsibility for abstracting the required data from the reporting physician's records. Within approximately six months of the physician submission, an abstractor is sent to the professional's office to gather clinical detail. It should be noted that in reality the California regional staff commonly collects information via phone or fax. Provisions exist to protect confidentiality of patients (e.g., information not pertinent to the cancer diagnosis/report can be "blacked out" of information given to abstractors).

There are 10 CCR regions in California. The law allows the Department of Health to designate areas as regional reporting areas and to establish multiple database regional registries. Operation and maintenance of CCR regional database registries can be contracted to local health agencies, county health departments, non-profit entities, etc. The California Department of Health establishes standards and procedures, yet the local control can effectively be subcontracted to local agencies that are more closely in touch with regional providers and facilities.

The central CCR in Sacramento collects regional information and performs quality control checks, as well as statewide analysis and reporting. The main purpose of the multiple database regional registries is to:

- Gather information from the physician offices and cancer reporting facilities that elect to have the regional registry do the cancer data collection;
- Receive electronic submissions from self-reporting facilities;
- Load data into the regional registry, compile, and consolidate;
- Perform quality control;
- SEER regions perform follow up on the vital status of the patient for survival analysis; and
- Provide data to the central office.

Currently, five of the smaller regions are on a shared database system called CANDIS. It is the intent of the CCR to restructure this shared registry. There are three additional independent database registries that include one to two California regions; therefore, there are a total of four multiple database registries in the California regions. Currently, the patient consolidation is done at the regional level. The region of patient residence at the time of patient diagnosis is the owner of the patient. Therefore, if a patient goes to another region for additional cancer services, this second region sends the information to the region of patient residence for incorporation into their regional database registry.

Once the central office receives all of the multiple regional database submissions, they do some work on duplicates at the state level. Any duplicates that are identified at the state level are sent back to the regions for them to determine who "owns" the patient. Duplicates occur at the state level when a patient is diagnosed with cancer in one region, then moves to another region to undergo treatment of the same cancer, and neither region is aware that the patient was seen elsewhere. The central office has historically addressed duplicates using random sampling of cases from the multiple regional databases. Any duplicates that are identified are sent back to the regions for them to determine the residency of the patient and the assigned region.

As the CCR moves toward a centralized registry system, duplicate resolution will involve the entire database.

The state would like to eventually go to a centralized database architecture, similar to the TCR in Texas; however, they are taking small steps towards this by initially consolidating the data from the four registries on a quarterly basis. There is some speculation that the SEER metropolitan areas will have to keep their own databases, since the SEER system is looking to create one standard SEER processing system. Therefore, many factors need to be assessed prior to becoming one consolidated statewide database.

One interesting aspect of the CCR data collection method includes the process for incorporation of pathologist information in the Los Angeles region. The Los Angeles regional office staff physically goes to all pathology labs (freestanding and hospital) and gets a photocopy of all pathology reports. When a hospital sends in information on a given patient, the regional staff attaches the pathology report to a copy of the hospital report and files it as completed. At the end of the year, each region looks to see how many pathology reports are left over. The regional office staff then solicit the healthcare provider (as defined in the pathology report) for more cancer information. Apparently, the pathology reports also offer opportunities for quality assurance, since they contain a great deal of the same information sent in by the hospitals.

It should be noted that the CCR receives grants for performing research using data from the CCR. These research grants have not been used to improve the CCR database.

VRI interviewed staff from the CCR and received the following information on the advantages and disadvantages to a multiple regional registry:

Advantages: The regional registries have local knowledge of the changing healthcare environment and understand patterns of diagnosis and treatment better. They have found that having personal acquaintances at the local registry level is beneficial to reporting. The cancer registrars and regional registry staff have been able to work together to gather cancer patient information. This working relationship benefits the timeliness of data reporting, since the regions have found that close communication with hospitals reduces delays in reporting. This working relationship also increases the completeness of the data, as is evident in the example presented above regarding the use of all pathology reports to ensure complete and accurate reporting by healthcare providers. Lastly, the regions feel they are able to collect the cancer incidence data quicker at the regional level than at the state level. This helps with research grants that need fast and sophisticated access to the data for rapid case ascertainment. It should be noted that the state will only move to a statewide database registry if over time they can prove that they will not lose the timeliness of patient cancer incidence data collection.

Disadvantages: California currently has four regional databases being maintained across the state. Each regional database is performing the same type of work in gathering cancer information in California. This takes much more staff and much more money than incorporating one central statewide database registry. The state is hard-pressed to justify the multiple database regional registries given the current

advanced technical environment, and is looking to create a statewide central registry in the future.

7.2 The Louisiana Tumor Registry Model

The Louisiana Tumor Registry (LTR) was originally established as part of the SEER program and began in New Orleans at Charity Hospital (now Medical Center of Louisiana) in 1974 with Federal funding. Cancer data were collected for Orleans, Jefferson, and St. Bernard parishes. In 1980, when Federal funding for the local registry stopped, the state began funding the registry and established the Louisiana Cancer and Lung Trust Fund Board, housing both within the Office of Public Health. By 1983, the Tumor Registry was collecting data from the 35 southern parishes of Louisiana. In 1988, expansion of the Tumor Registry encompassed data collection activities in every parish of the state, through a network of eight regional registries. The multiple regional registries continue to provide data to the central office. In 1995, the Louisiana Tumor Registry (Central Office), and the Louisiana Cancer and Lung Trust Fund Board were administratively moved from the Louisiana Office of Public Health to the Louisiana State University Medical Center in New Orleans.

The multiple regional database registries receive some of their funding from a local university or a health association. Very few physicians actively report to the LTR. The large hospitals, which provide two-thirds of the reports, do their own abstracting and report their cancer information to their respective regional registry. The regional field representatives abstract at the small hospitals and outpatient surgery and radiation centers and enter the patients' cancer information into registry software. Large pathology laboratories send diagnosis information, including physician name, to the regional registries. When a pathology report identifies a patient on whom the LTR has no supporting cancer information, the LTR contacts the physician (as noted on the pathology report) and asks for cancer information on the patient. Physicians usually respond with the necessary information.

The regional office consolidates all of the cancer information and then forwards it on to the central office. The central office consolidates all of the regional submissions into one statewide database. The central office also creates annual reports and responds to data requests from news media, healthcare providers, students, and other concerned citizens.

Louisiana law permits follow-up information on a case (if available in the LTR) to be provided to the facility that originally submitted the case. This was created to ensure that Louisiana was helping hospitals do their follow up as much as possible.

VRI interviewed staff that worked at the LTR and received the following information regarding the advantages and disadvantages of a regional registry:

Advantages: The regional registries are able to create an environment of local responsibility to motivate the local facilities to report. The regional registry staff members are also better acquainted with their healthcare providers than staff from the central office and may be better situated to respond to central office edit queries involving hospital charts and to follow back on death certificate reports.

Disadvantages: The regional database registries add another layer in the process of data processing. This may result in delays in data collection and compilation at the central level. Delays are not inevitable, however, as regional edits eliminate many problems that central editors would have to resolve. After the regional offices consolidate duplicate reports on a given case, the central office also must de-duplicate and consolidate reports coming from two or more regions. Data would probably be available more quickly if the central office performed all of the data editing and consolidation.

When Louisiana created its statewide registry in 1988, technology was not what it is today, and the political environment in Louisiana at the time perceived a need for some local oversight. The staff that was interviewed felt that with current technology for networks and data management, it might be beneficial to rely on centralized data processing. Although the multiple regional registries facilitate data gathering, this impacts data editing and consolidating, and it is here that modern data transmission and centralized data processing capacities are probably more efficient.

Recommendations: There appear to be no real technical advantages to incorporating a multiple database regional registry infrastructure. Given the current technical environment, there would be no substantial improvements in data quality, or in the timeliness of data collection. In fact, it appears as if the additional layer of regional registry data collection only adds to the effort in gathering consolidated statewide cancer information.

In addition, this would be an enormous undertaking to incorporate, given the existence of a centralized database statewide registry infrastructure in Texas. However, there are programmatic benefits to a multiple database regional registry. In the scenario of the central office being owned by the state and the regional database registries being contracted out, there would be no state health department restrictions on the regional registries. This would enable the regional registries to hire staff and invest in the registry as needed, independent of state restrictions. In addition, the regional registries could look to local medical schools or universities for cost sharing of the registry. There is also the local buy-in of having a regional database registry and no state restrictions on the sharing of the data with reporters; therefore, reporters may have better access to the data.

If a multiple database regional registry is being considered, there are four ways to implement regional registries from a technical standpoint.

1. Each TCR regional office could operate a SandCrab system independently and submit data to a central office on a regular basis. This solution would have no technical advantage and could increase the cost by requiring additional system administration staff. It also would mean that the data take longer to arrive to the final destination, the central office. This solution offers no substantial improvement in data quality or timeliness in data collection.

2. Another solution is to create a distributed database such that each region has a regional database that is able to communicate with all the others and share the data so that it functions as one entity. This is costly in terms of creating the system with this capability and in staffing system operations at each site. The advantage is mostly the perception of data belonging to a region yet having the

capability to access all data from a central office at any point in time. This solution offers no substantial improvement in data quality or timeliness in data collection.

3. A third method is to allow a group of facilities in a region to take responsibility for collecting data for their select population using a system of their choice, and then submitting these data to the central office on a regular basis just as other large facilities submit electronic data. This could improve quality and timeliness based on benefits perceived by the group of reporting facilities involved. This would require enforcing rules for regular submission, otherwise there would be further delays to having complete and consolidated statewide data. This type of regional registry, or pooling of resources, should be encouraged regardless of any other regional registries or solutions that are put in place. Since it would be a privately run registry, the region's set of rules for their operations would not be within the TCR's domain.

4. A fourth method would be to continue running the main system out of the central office, owned by the state, and have the regional registries contracted out. This would enable the regional registries to hire the staff they needed and spend money on the registry without any state restrictions. In addition, the regional registries could look to local medical schools or universities for cost sharing of the registry. This solution could be implemented with multiple SandCrab systems at the regions or using other commercial products for cancer registries. Rules and regulations would need to be put in place to maintain the quality assurance and other procedures currently enforced at the central office. Additional procedures would need to be defined for enforcing regular data submission, cross-region consolidations, and handling corrections for errors discovered by the central office.

The state needs to determine if there are available contractors with the expertise needed to create a usable and efficient regional registry. It also needs to be determined if there is interest at the regional level to create and maintain the registries. The state needs to develop cancer registry standards and data quality requirements. TCR staff suggested that the state initially set up pilot sites to assess the feasibility of the regional registries. This method would ensure the greatest success. The pilot sites should follow the same methodology that would be used to incorporate a regional registry. This means that the TCR needs to develop standards, create a contract specification for a thorough requirements analysis of the pilot registry, evaluate the RFPs to see if they have the capability and then have a contractor work on a pilot study regional registry database. Once the requirements analysis has been performed, the contractor can install the system and evaluate its effectiveness and report back to the TCR their recommendations on implementing multiple or distributed regional registries with the rest of the state.

8.0 Summary Recommendations

Technical and process recommendations can be divided into three broad classes based upon the degree of change necessary from current TCR infrastructure and processes:

- **Minor system enhancements** include recommendations that are based on maintaining the current system mostly unchanged and implementing improvements that do not substantially modify current TCR infrastructure or processes.
- **Intermediate system enhancements** include solution recommendations that would typically involve at least some level of additions and modifications to the current TCR infrastructure and related system processes.
- **Major system enhancements** entail improvements to the TCR with system and process modifications that are substantial, and would likely be associated with larger costs. Although more resource-intensive, these solutions also imply longer-term benefits.

Although not strictly required, these recommendations may be implemented incrementally and successively build upon prior TCR enhancements.

Many of the process suggestions identified in this paper need to be more fully evaluated in terms of their feasibility and ability to mitigate the factors which ultimately affect TCR timeliness, accuracy, and completeness. However, based upon the current assessment, the greatest benefits would likely be gained from redesigning the current SandCrab system. In the long term, the existing SandCrab system will continue to have difficulty incorporating new functionality, storing larger amounts of data, and allowing more users to access the system due to limitations inherent to the product used to create the software (i.e., FoxPro). It should be noted that the FoxPro software is no longer supported by the vendor, increasing the need for a more current and supportable system.

With those issues in mind, the redesigned TCR system should fully incorporate all system requirements and employ a more robust database management system that is scalable, allows for technology expansion such as Web functionality, and is designed to be more easily enhanced as new requirements evolve. As such, the enhanced TCR system would enable connectivity and electronic communication with a large number of users, taking full advantage of current and evolving technologies.

The various system enhancements are discussed in the following sections.

8.1 Minor System Enhancements

Several technical solutions identified as important by TCR staff would improve current operations, but would not require substantial modifications to existing TCR infrastructure. Some of these solutions are already partially designed and implemented, such as modifications to the regional staff software to eliminate the problems of inadequate speed and the inclusion of some the SandCrab functionality

that has hampered the efforts of regional staff. Another modification requiring only minor infrastructure modifications is the implementation of an automated patient record consolidation function. Other modifications in this category include incorporating on the TCR Web site the types of reports and graphs requested by end users, providing links to relevant sites, and providing secured cancer reports for researchers. Ultimately, a central Web site should be created that will serve as a central point of contact for all published and disseminated forms of cancer data, as well as users (or organizations) of cancer data in the cancer prevention and control effort. The TCR Web site could be enhanced to become this site, or another Web site could be created or expanded to become the cancer gateway and provide a link to the TCR Web site.

In terms of process-related solutions, one enhancement that would require only minor changes is having more regional involvement with reporters. The Lubbock region could be used as an example of how regional offices might better assimilate the reporters with TCR objectives. The regional staff could foster the education of reporters on issues such as the importance of reporting to the registry, proper cancer case reporting, and how TCR data are being used in research. The regional staff should also share reporter "best practices" information to increase reporter efficiency. The TDH and TCR stakeholders should encourage the small and medium hospitals and physician offices to pool their resources and use certified tumor registrars for cancer reporting, and to try and attract more certified tumor registrars to Texas. The TCR should also work with the national cancer reporting standard setting organizations to affect the continuous changes to reporting standards and improve timely notification and documentation. Lastly, the TCR should also look into developing rules and regulations for patient street address consistency, so that all patient residences can be geo-coded.

Exhibit 8-1: Proposed Minor System Enhancements

Enhancement	Type
Modifications/improvements to regional staff software.	Infrastructure
Implementation of automated record consolidation function.	Infrastructure
Incorporate reports, graphs, relevant site links, and secured end user information on TCR Web site.	Infrastructure
Provide cancer gateway on the Internet.	Infrastructure
Increased regional staff involvement.	Process
Encourage and attract certified tumor registrar usage by small and medium hospitals and physician offices.	Process
Work with national standard setting organizations	Process
Develop rules and regulations for street address consistency.	Process

8.2 Intermediate System Enhancements

System changes judged to be of intermediate complexity are those requiring some changes to current TCR operations, and potentially involve the distribution of new software to reporters. Under this scenario, TCR staff and reporters may need to be trained on how to use the new software and follow new procedures. One such solution involves creating an application that allows users to submit electronic files that are sent directly to the TCR for immediate processing, placing the responsibility on reporters to send usable submissions. Another solution involves creating an enhanced version of SandCrab Lite that incorporates many of the Windows standards and features that are commonplace in software applications and increasingly familiar to PC users. This enhanced version of SandCrab Lite would also provide reporters with the ability to connect to the TCR to correct data errors, add specific missing fields, generate selected reports, and upgrade their software when appropriate. Another solution judged to be of intermediate complexity is the development of a version of SandCrab Lite for physicians that would be customized for each type of physician reporter.

As these solutions are implemented and grow more popular, it will become increasingly important that TCR hardware and communications infrastructure be upgraded to support a larger number of concurrent users, as well as larger volumes of input information and data edits. Enhancements of this nature would include hardware upgrades to allow more lines dialing in, enhanced server capabilities to support increased levels of concurrent processing, and switching the database to a system that better supports a multi-user environment. Specific system design decisions would need to be based on the expected number of concurrent users, the average volume of input data, the desired response time, and a variety of security issues.

Several intermediate level process solutions exist that would require some degree of change in current TCR processes and infrastructure. One example is active regional participation in gathering reporter information. The TDH and TCR might consider having the regional registries gather information from the small hospitals and physicians, similar to the process used in California. In addition, guidelines should be developed to support and encourage the development of local networked registries by reporters. These guidelines should identify where the development of local networked registries are appropriate and define a core set of standard requirements that are consistent across all local networked registries. The TCR might also create FAX-back forms for physicians who would like to submit their data in a paper form, and who do not want an abstractor to come to their facility to gather information. One such scenario could have the faxed image directly scanned into input data for the TCR.

When the current state legislation regarding privacy is finalized, the TDH should perform a thorough requirements analysis to assess the implications of the HIPAA regulations and the state legislation on the current TCR infrastructure. Unless forbidden by those regulations, opportunities should be made for including limited access to the TCR data by reporters and end users. This should be considered wherever possible since this request was made by nearly all of the focus group members.

Exhibit 8-2: Proposed Intermediate System Enhancements

Enhancement	Type
Create application for automatic submission of electronic reporter data.	Infrastructure
Upgrade SandCrab Lite and take advantage of Windows features.	Infrastructure
Allow reporters limited access to the TCR for correcting data, adding missing fields, etc.	Infrastructure
Develop a customized "SandCrab Lite for Physicians".	Infrastructure
Incorporate hardware upgrades as necessary to accommodate technical enhancements.	Infrastructure
Incorporate active regional participation for cancer data collection.	Process
Develop guidelines for local networked registry development.	Process
Create FAX-back forms for physician reporting.	Process
Evaluate implications of HIPAA regulations and pending state legislation regarding privacy.	Process

8.3 Major System Enhancements

Major system changes would involve a complete TCR system requirements analysis, a detailed design, and new SandCrab software with enhanced features. This new system would support the current processes, plus any of the desired recommendations and enhancements in a well-integrated system. The revised system would offer substantial improvements in flexibility over the current system, allowing system modifications in a more modular fashion, without necessitating complete system replacement as TCR requirements continue to change and technology advances. This version of the enhanced TCR would be scalable to support more users and faster queries as the demands on the system increase.

The revised version of the TCR system could potentially be achieved through either of two approaches. The first approach is through the development of customized TCR software. This alternative offers the most flexibility as well as the greatest likelihood of integrating the numerous enhancements identified here. The customized software product would be the property of the funding agency (e.g., TDH), and therefore could be enhanced at any future date, should the need arise. Although this option offers many potential benefits, there are several risks that should also be recognized. Customized software development is typically labor-intensive, and therefore may require a substantial investment. Depending on the specific design being implemented, these efforts may be subject to a variety of technical, schedule, and resource risks. Ideally, a customized software development effort will yield a product that balances these benefits and risks, providing the desired functionality with acceptable costs over the lifecycle of the system.

Another option is to look for a commercial off-the-shelf (COTS) cancer registry product. However, the risks here are difficulties in meeting expectations in satisfying current requirements, quality of product, and guarantees of long-term support. Since a COTS software solution would not be the TCR's product, the source code would not be available for ad hoc customization and the TCR would not be able to make enhancements, fix bugs, or maintain the system in the long run. Until there is a

product available that several states have been successfully using for a statewide registry, it would be risky for Texas to purchase an untested product.

Exhibit 8-3: Proposed Major System Enhancements

Enhancement	Type
Re-design the current SandCrab software. • Incorporate all system requirements in a well-integrated system. • Develop a more powerful and scalable database platform. • Allow for more interactions with reporters by allowing direct transmissions of data and feedback electronically. • Allow for evolving technologies and networked computing over the Internet. • Include system flexibility that allows for system modifications in a modular fashion.	Infrastructure

8.4 Summary of System Enhancements

Exhibit 8-4 shows how these minor, intermediate, and major system changes address the reported issues affecting use of the current TCR.

Exhibit 8-4: Issues Addressed by Proposed System Enhancements

Reported Issue	Enhancement	Impact on Current TCR Infrastructure	Enhancement Type
Participation Seen As A Burden/Reporters Apathetic about Reporting	(1) Increased regional staff involvement (2) Incorporate reports, graphs, relevant site links, and secured end user information on TCR Web site	(1) Minor (2) Minor	(1) Process (2) Infrastructure
Insufficient Staff or Staff Knowledge (or Technology)	(1) Increased regional staff involvement (2) Encourage and attract certified tumor registrar usage by small and medium hospitals and physician offices (3) Incorporate active regional participation for cancer data collection (4) Develop guidelines for local networked registry development	(1) Minor (2) Minor (3) Intermediate (4) Intermediate	(1) Process (2) Process (3) Process (4) Process
Lack of Electronic Linkages to Different Sources of Data	Incorporate active regional participation for cancer data collection	Intermediate	Process
Reporters Want to See TCR Data on Their Patients	Allow reporters limited access to the TCR for correcting data, adding missing fields, etc.	Intermediate	Infrastructure
Reporters Unsure of Proper Cancer Reporting	Increased regional staff involvement	Minor	Process
Reporters and End Users Need More Local Support	Increased regional staff involvement	Minor	Process
Duplication of Effort When Facilities Submit Data for the Same Patient	Develop guidelines for local networked registry development	Intermediate	Process
Reporters Discouraged That Submissions May Not be Processed in a Timely Manner	Create application for automatic submission of electronic reporter data	Intermediate	Infrastructure

Reported Issue	Enhancement	Impact on Current TCR Infrastructure	Enhancement Type
Patients Submitted by Physicians May Already Exist in the Registry	(1) Encourage and attract certified tumor registrar usage by small and medium hospitals and physician offices (2) Develop a customized "SandCrab Lite for Physicians"	(1) Minor (2) Intermediate	(1) Process (2) Infrastructure
Concerns About Patient Confidentiality and Office Disruption	(1) Create FAX-back forms for physician reporting (2) Develop guidelines for local networked registry development	(1) Intermediate (2) Intermediate	(1) Process (2) Process
Impression of Physicians That Their Own Participation is Not Important	Increased regional staff involvement	Minor	Process
Limitations of SandCrab Lite	Upgrade SandCrab Lite and take advantage of Windows features	Intermediate	Infrastructure
Multiple Versions of SandCrab Lite in Use	Upgrade SandCrab Lite and take advantage of Windows features	Intermediate	Infrastructure
TCR Burdened by Continuous Changes to Cancer Reporting Requirements	Work with national standard setting organizations	Minor	Process
Central Office Processing Burdened by Incomplete or Incorrect Submissions	Create application for automatic submission of electronic reporter data	Intermediate	Infrastructure
Central Office Wastes Time Handling Duplicate Submissions	Create application for automatic submission of electronic reporter data	Intermediate	Infrastructure
Central Office Consolidating Multiple Patient Records by Hand is Burdensome	Implementation of automated record consolidation function	Minor	Infrastructure
Central Office Obstacles to Geo-Coding Patient Address Information	Develop rules and regulations for street address consistency	Minor	Process
Central Office Difficulties Incorporating Corrections in a Timely Manner	(1) Create application for automatic submission of electronic reporter data (2) Upgrade SandCrab Lite and take advantage of Windows features	(1) Intermediate (2) Intermediate	(1) Infrastructure (2) Infrastructure
Transmission Line Traffic Slows Regional Offices Using SandCrab Online	Modifications/Improvements to regional staff software	Minor	Infrastructure
Regional Offices Do Not Have Access to All SandCrab Functionality	Modifications/Improvements to regional staff software	Minor	Infrastructure

Reported Issue	Enhancement	Impact on Current TCR Infrastructure	Enhancement Type
Limitations of Current SandCrab and SandCrab Lite for Expanded Use	(1) Upgrade SandCrab Lite and take advantage of Windows features (2) Incorporate hardware upgrades as necessary to accommodate technical enhancements (3) Re-design the current SandCrab software	(1) Intermediate (2) Intermediate (3) Major	(1) Infrastructure (2) Infrastructure (3) Infrastructure
Poor Timeliness of Data	*Multiple enhancements would benefit the timeliness of cancer data processing*	*Minor/ Intermediate/ Major*	*Infrastructure and Process*
TCR Reports Need Enhancements	(1) Incorporate reports, graphs, relevant site links, and secured end user information on TCR Web site (2) Provide cancer gateway on the Internet	(1) Minor (2) Minor	(1) Infrastructure (2) Infrastructure
Difficulty Accessing Detailed Data	Incorporate reports, graphs, relevant site links, and secured end user information on TCR Web site	Minor	Infrastructure
Health Insurance and Portability and Accountability Act Regulations	Evaluate implications of HIPAA regulations and pending state legislation regarding privacy	TBD	TBD
Pending State Legislation Regarding Privacy	Evaluate implications of HIPAA regulations and pending state legislation regarding privacy	TBD	TBD

TBD = To Be Determined. The implications of these regulations need to be evaluated via a requirements analysis to determine the impact on the current TCR infrastructure.

9.0 Next Steps

VRI is recommending five high-level steps to implement TCR enhancements.

1. Review and Prioritize Recommendations.
2. Assess Specifications and Implement Desired Functional Solutions.
3. Assess Specifications for Desired Technical Solutions.
4. Issue RFP to Contract for Infrastructure Improvements (if necessary).
5. Implement Technical Solutions.

These steps are described in this section.

9.1 Review and Prioritize Recommendations

The first step for the TDH is to review the recommendations from this study in conjunction with anticipated budgets for TCR enhancement, design, and development. In addition, the resources available for TCR enhancements and operations will need to be reconciled with other competing priorities, timeline expectations, as well as emerging policies that may influence system design. Therefore, it is recommended that the TDH continue to collaborate with key TCR stakeholders to determine which recommendations offer the most attractive alternatives, given existing priorities and constraints. The TDH may also look to ongoing external support (e.g., institutionalized support, a formal advisory board) for the long-term management of the issues. The evaluation of enhancements and their implementation will require a long-term investment that may be best handled by a formal body of the TDH, possibly an advisory committee that will be able to provide institutionalized support.

In general terms, two tracks exist for the enhancements to improve TCR data quality, relating to process and infrastructure improvements, respectively. Although these two broad areas of enhancement may at times be pursued in parallel, the recommended TCR process improvements should be considered and prioritized as soon as possible, since the adoption of the processes could influence system requirements for hardware, software, and communications.

9.2 Assess Specifications and Implement Desired Functional Solutions

All functional (i.e., process) solutions will require development of an implementation plan, staffing and training of necessary staff (where applicable), and feedback mechanisms for assessing effectiveness and incorporating relevant modifications as necessary. It will be important for the TDH to continue collaboration with key TCR stakeholders to determine which recommendations offer the most attractive

alternatives and how they may be implemented. The process solutions also need to offer flexibility for the different types of reporters.

9.3 Assess Specifications for Desired Technical Solutions

All technical (i.e., infrastructure) solutions will require a thorough requirements analysis, system design, and system implementation plan. The requirements analysis formally establishes the attributes of the desired TCR enhancements at a high level for which detailed specifications will need to be developed. The system design would include details such as case scenarios, screen mock-ups, communications analysis, and high-level diagrams of the interactions. Note that following the requirements analysis, it would be possible to estimate price ranges for alternative solutions. Although these estimates would not represent the precise cost of the enhancements, they would be sufficient for TCR budgeting and timeline planning.

9.4 Issue RFP to Contract for Infrastructure Improvements (if necessary)

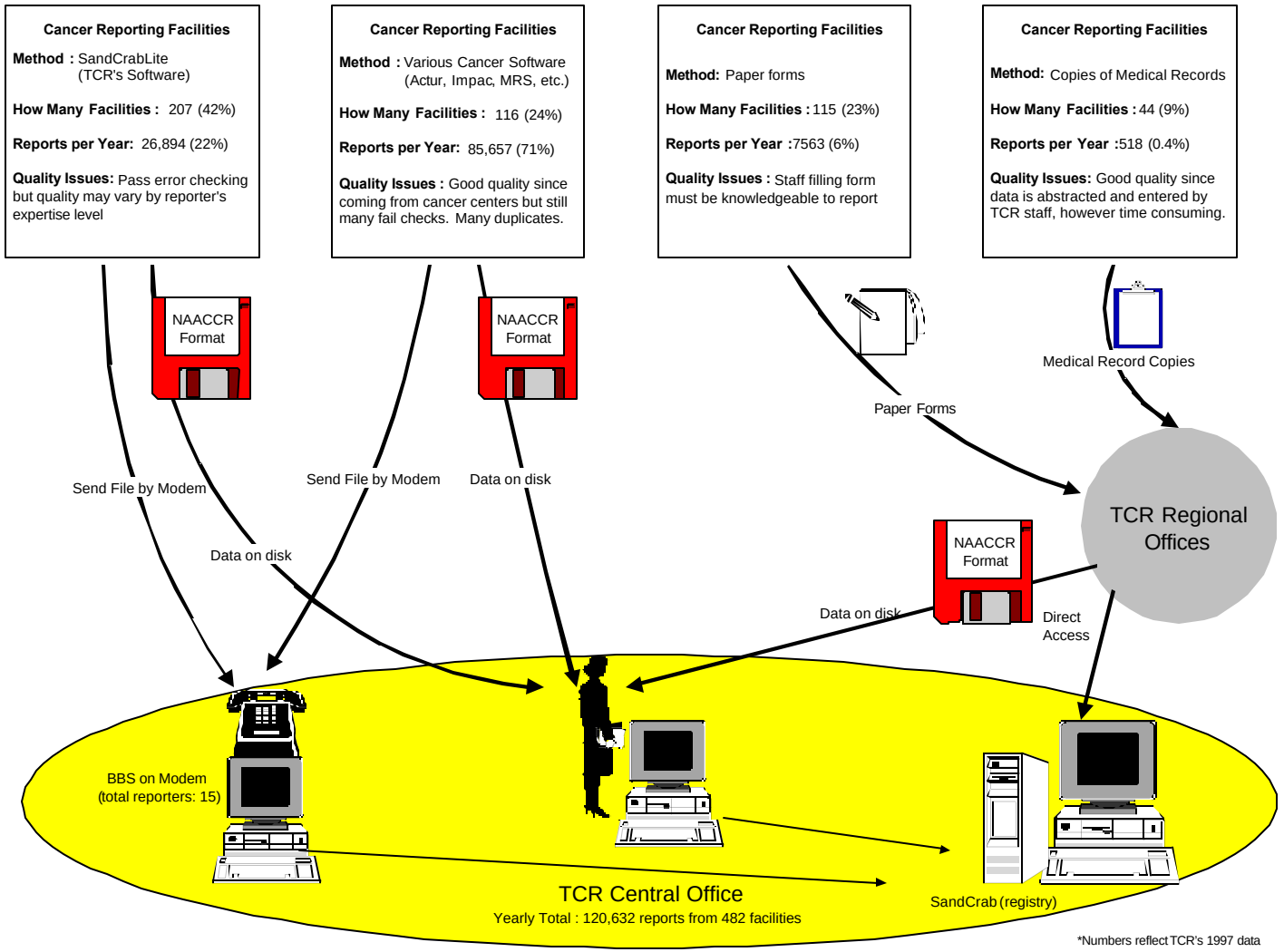
Subsequently, a request for proposal (RFP) would be necessary, assuming the TDH would seek contractual assistance for the TCR infrastructure improvements. In order to support that process, the TDH would need to develop the standards and contract specifications for inclusion in the RFP, as well as convene source selection committees to evaluate and score responses to the RFP. The RFP development will require TDH review of existing state polices on technology standards, compliance with the Health Insurance Portability and Accountability Act (HIPAA), and may possibly require coordination with other agencies. Note that the proposal review process could generate additional recommendations at a lower level of detail based upon the specific content of the TCR requirements in the RFP, such as technical constraints that may restrict the tools selected. As an example, if it is decided to continue to use FoxPro for SandCrab, this may mean some code will be reused, but it can also preclude certain technical options or increase the difficulty of implementation and affect the cost.

9.5 Implement Technical Solutions

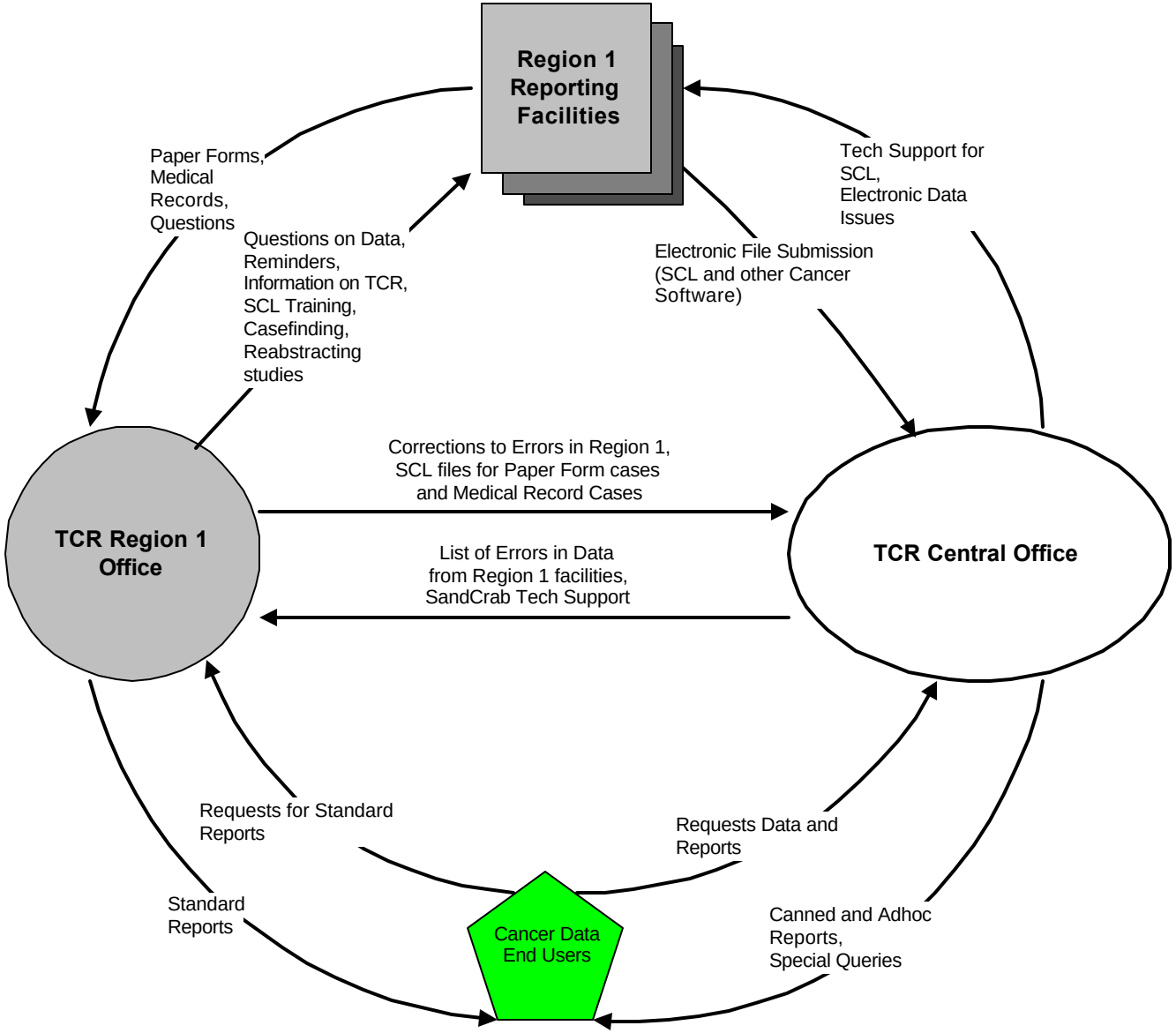
The last step would be to select programmers or contractors who would fully implement and test the enhanced TCR software, including appropriate documentation and training. Depending on the technology solutions chosen, a pilot test may also be appropriate to assess additional user needs that should be incorporated prior to full deployment.

Appendix A: Current TCR Information Architecture

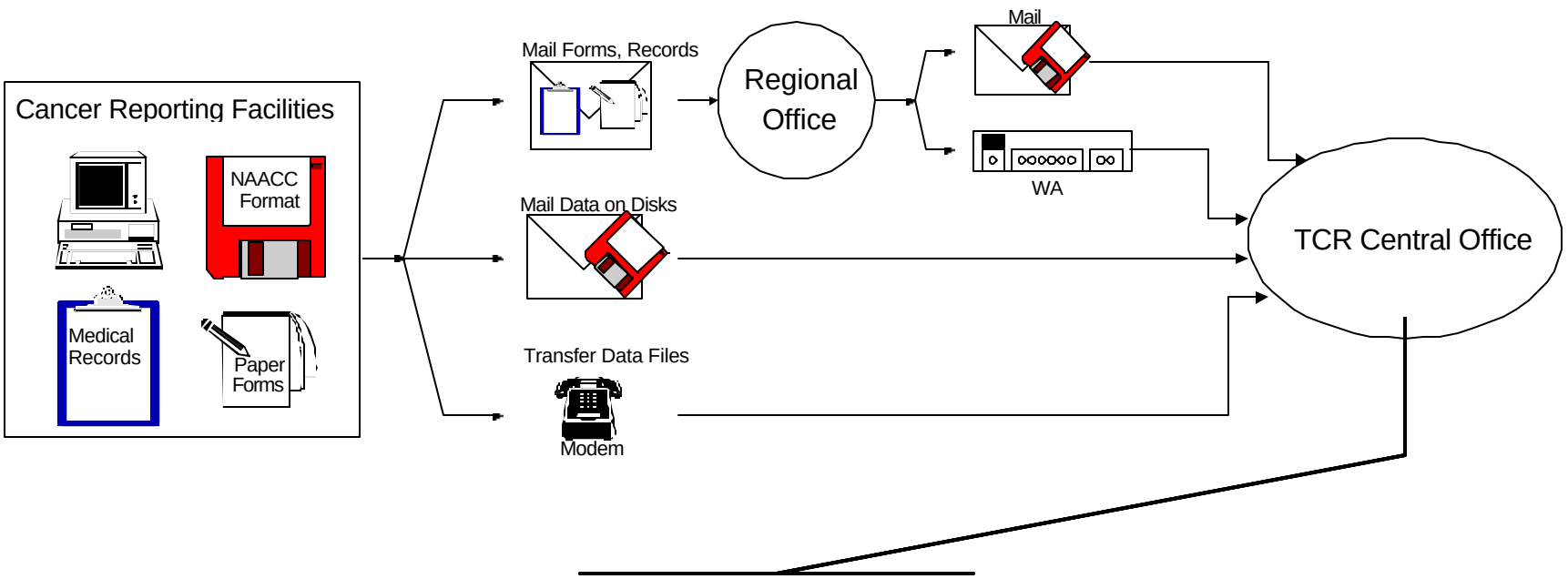
Current Methods for Reporting Data to Texas Cancer Registry



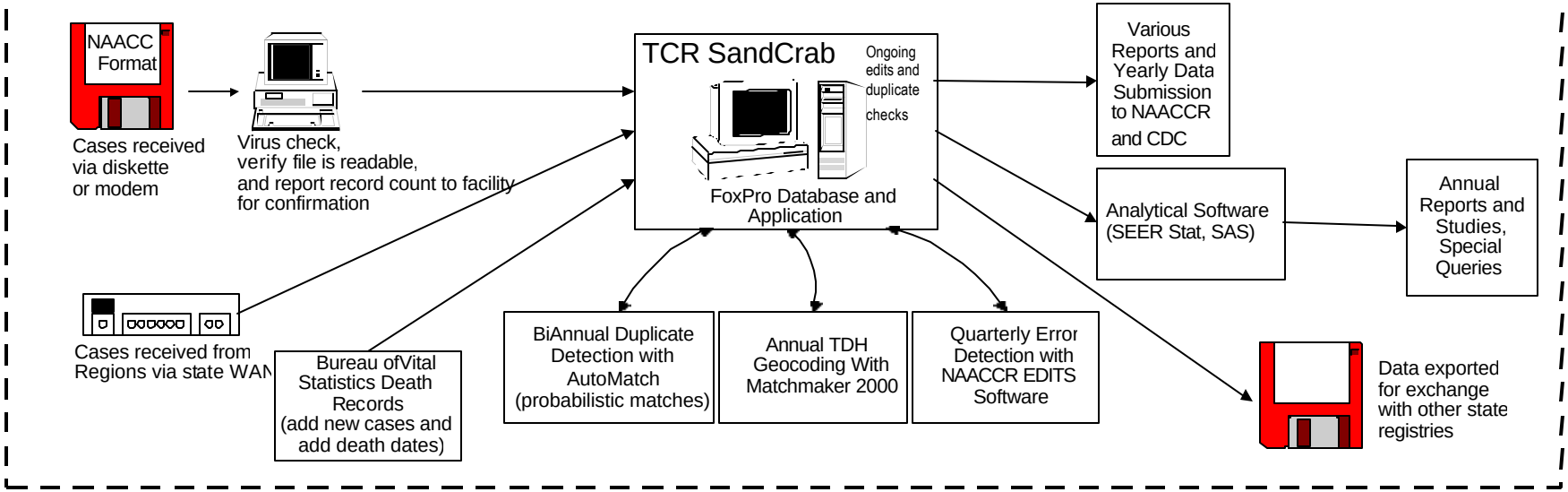
Interaction Between TCR Participants



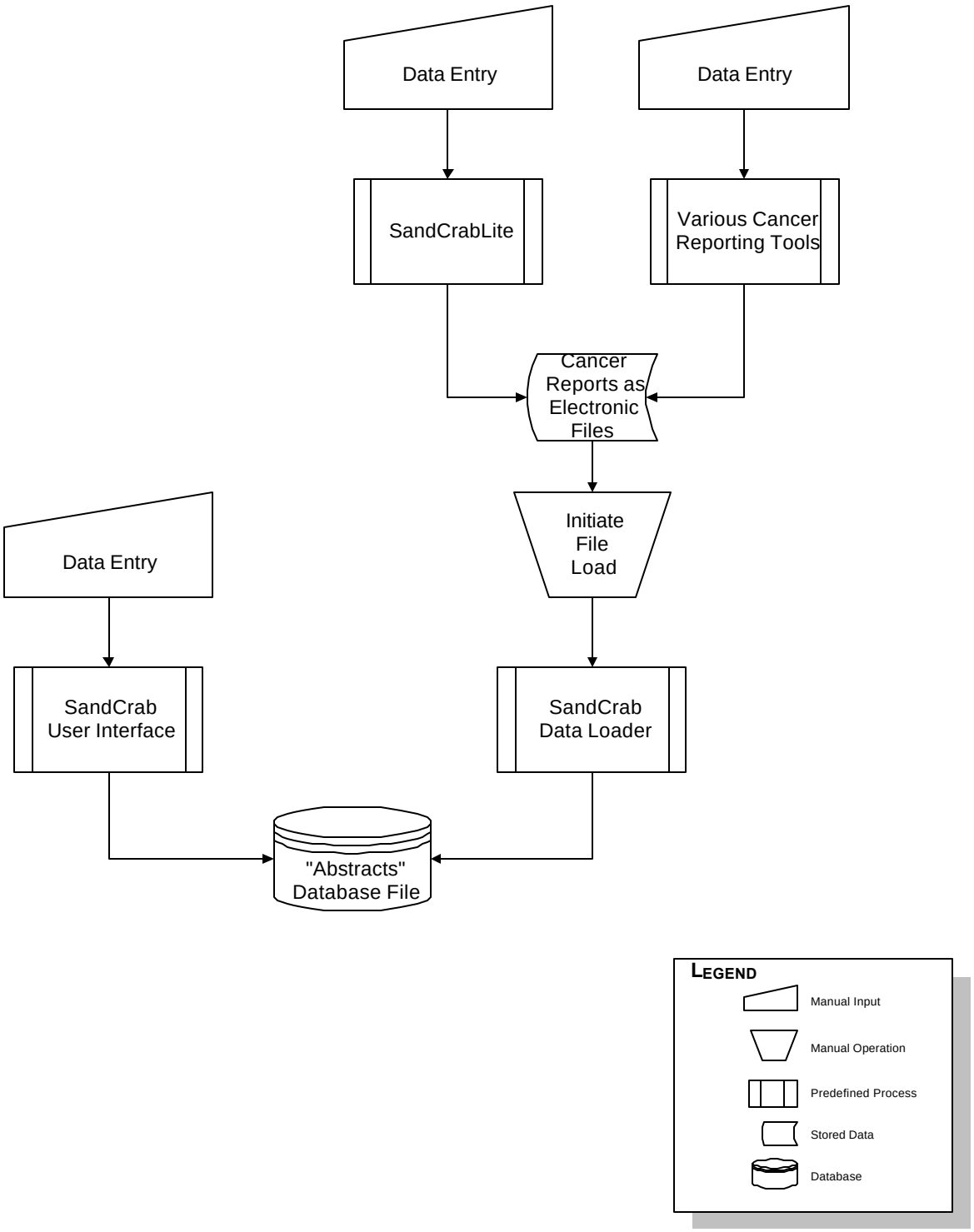
Journey of a Cancer Report



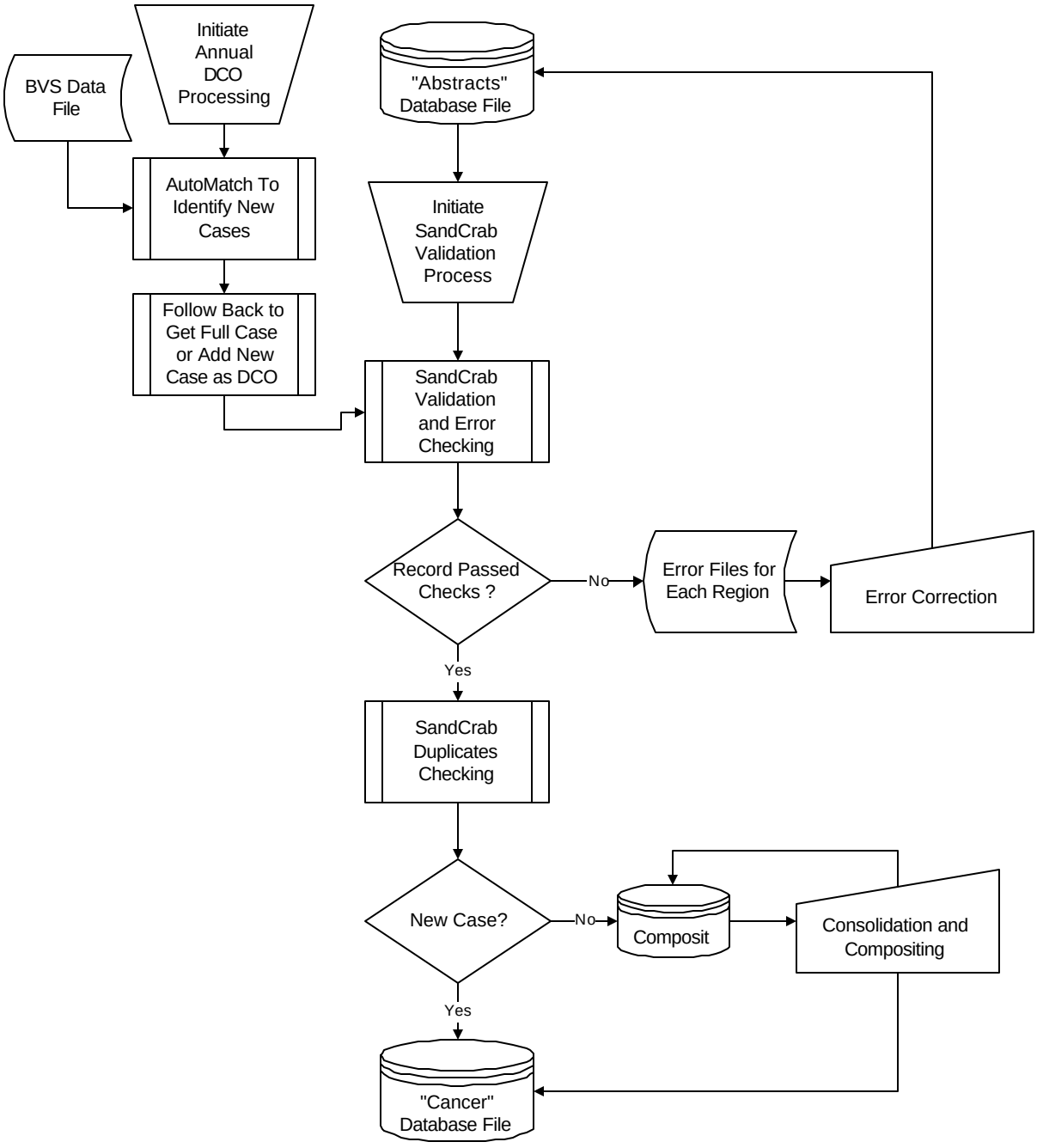
AT THE TCR CENTRAL OFFICE



Getting Data into TCR Abstracts Table
(Processing for all Cancer Records Received)

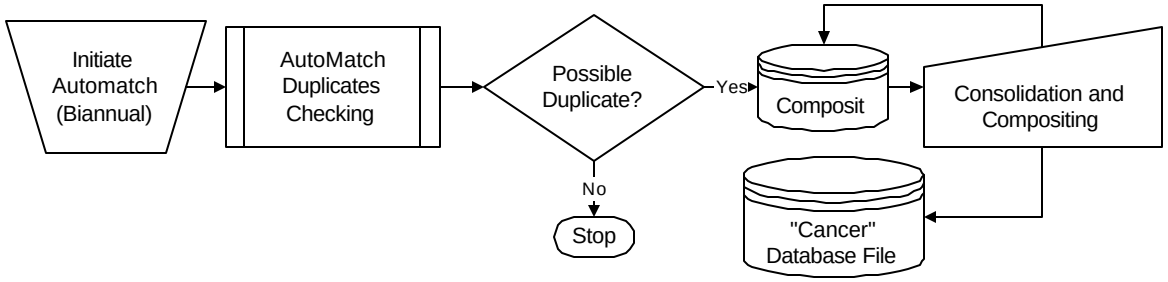


Getting the Data into the TCR Cancer Table

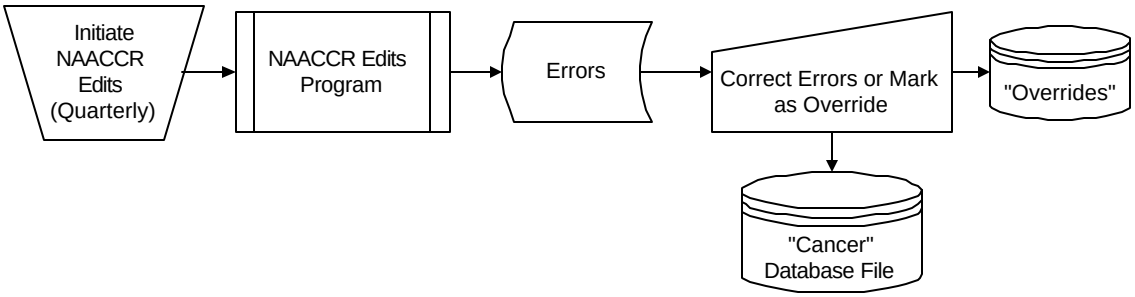


Additional Processing on Cancer Table Data

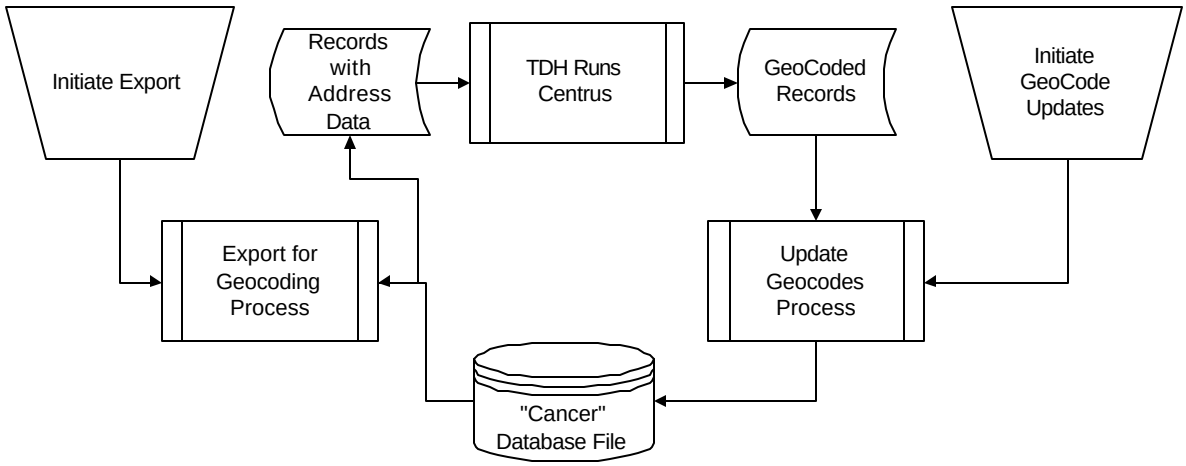
AutoMatch Duplicate Check



NAACCR EDITS



GeoCoding Records



Appendix B: Focus Group Categories and Topics

B.1 Focus Group Category: Reporters

B.1.1 Focus Group Members

1. Hospitals –
   - Small < 50 beds
   - Medium = 50–150 beds
   - Large = 150+ beds
   - Large hospital cancer registries
2. Nursing homes/hospices
3. Cancer treatment centers
4. Outpatient surgery centers
5. Dentists
6. Physicians
7. Pathology labs
8. SandCrab Lite developers and other cancer registry software developers
9. CEO/High level administrators of healthcare
10. Texas Tumor Registrars Association (TxTRA)

B.1.2 Topics

B.1.2.1 Technical

1. Reporting requirements
2. Parameters and predictors of complete, timely, accurate cancer reporting
3. All cancer reporting software utilized by reporters (e.g., SandCrab Lite)
4. Barriers to reporting
5. Ideal reporting process
6. What is the "current" process
7. HIPAA implications for stakeholders
8. HHS privacy rules and implications
9. Additional privacy and confidential requirements of reporting beyond HIPAA and HHS
10. Attributable outcome reporting
11. Concerns of data linkages
12. Resource issues (as it pertains to software and hardware needs or deficiencies)
13. Compliance system monitoring/enforcement/benchmarks
14. TCR reporting in relation to other required state reporting.

B.1.2.2 Non-Technical

1. Resource issues
2. Professional responsibility
3. Personnel issues
4. Administrative support
5. Personal issues (e.g., interest, time)

6. Incentives to reporting
7. Organizational structure (e.g., state, regional)
8. Dissonance regarding value of reporting vs. pain of reporting
9. Potential uses of *good* cancer data

B.2 End Users

B.2.1 Focus Group Members

1. CEO/High level administrators of healthcare
2. Local/County public health officials
3. Physicians
4. Academic researchers

B.2.2 Topics

B.2.2.1 Technical

1. What is the "current" process
2. HIPAA implications for stakeholders
3. HHS privacy rules and implications
4. Attributable outcome reporting
5. Concerns of data linkages
6. Data availability and data users
7. Data validity and data reliability
8. End user needs
9. Input on observed reporter issues
10. Compliance system monitoring/enforcement/benchmarks
11. Parameters and predictors of complete, timely, accurate cancer reporting
12. Compliance system monitoring/enforcement/benchmarks

B.2.2.2 Non-Technical

1. Organizational structure (e.g., state, regional)
2. Dissonance regarding value of reporting vs. pain of reporting
3. Potential uses of *good* cancer data
4. Resource issues
5. Professional responsibility
6. Personnel issues
7. Administrative support
8. Personal issues (e.g., interest, time)
9. Administrative support
10. Incentives to reporting

B.3 IM/IT Personnel

B.3.1 Focus Group Members

1. HIM managers/directors — Military and VA
2. SandCrab Lite developer
3. Other cancer registry software vendors
4. Other IM/IT infrastructure personnel
5. TCR staff

B.3.2 Topics

B.3.2.1 Technical

1. IM/IT infrastructure capability stakeholders
2. Compliance system monitoring/enforcement/benchmarks
3. Reporting requirements
4. Parameters and predictors of complete, timely, accurate cancer reporting
5. All cancer reporting software utilized by reporters (e.g., SandCrab Lite)
6. Barriers to reporting
7. Ideal reporting process
8. What is the "current" process
9. HIPAA implications for stakeholders
10. HHS privacy rules and implications
11. Attributable outcome reporting
12. Concerns of data linkages
13. TCR reporting in relation to other required state reporting.
14. Resource issues (as they pertain to software and hardware needs or deficiencies)

B.3.2.2 Non-Technical

1. Organizational structure (e.g., state, regional)
2. Dissonance regarding value of reporting vs. pain of reporting
3. Resource issues
4. Professional responsibility
5. Personnel issues
6. Administrative support
7. Personal issues (e.g., interest, time)
8. Administrative support
9. Incentives to reporting

B.4 Government Officials/Funders/Regulators

B.4.1 Focus Group Members

1. CDC experts
2. Funding partners
3. Elected government officials

B.4.2 Topics

B.4.2.1 Technical

1. HIPAA implications for stakeholders
2. HHS privacy rules and implications
3. Reporting requirements
4. Parameters and predictors of complete, timely, accurate cancer reporting
5. All cancer software utilized by reporters (e.g., SandCrab Lite)
6. Barriers to reporting
7. Ideal reporting process
8. Attributable outcome reporting
9. Concerns of data linkages

B.4.2.2 Non-Technical

1. Political implications, constituency interests, consensus
2. Resource issues
3. Professional responsibility
4. Administrative support
5. Incentives to reporting
6. Organizational structure (e.g., state, regional)
7. Dissonance regarding value of reporting vs. pain of reporting

B.5 Professional Constituent Groups

B.5.1 Focus Group Members

1. State medical associations
2. Specialty societies (e.g., Texas Society of Pathology, Texas Society of Medical Oncology)
3. Local/County public health officials
4. Local medical societies
5. American Cancer Society
6. TMA
7. American College of Surgeons
8. Texas Tumor Registrars Association (TxTRA)

B.5.2 Topics

B.5.2.1 Technical

1. TCR reporting in relation to other required state reporting
2. End user needs
3. Identify best "practices" for increased performance
4. Reporting requirements
5. Parameters and predictors of complete, timely, accurate cancer reporting
6. Barriers to reporting
7. Ideal reporting process
8. HIPAA implications on stakeholders
9. HHS privacy rules and implications
10. Attributable outcome reporting

B.5.2.2 Non-Technical

1. Political implications, constituency interests, consensus
2. Resource issues
3. Professional responsibility
4. Administrative support
5. Incentives to reporting
6. Organizational structure (e.g., state, regional)
7. Dissonance regarding value of reporting vs. pain of reporting
8. Personnel issues
9. Personal issues (e.g., interest, time)

Appendix C: Focus Group Category Stem Questions

C.1 Focus Group Category = Reporters

1. How do you gather the cancer data for submission to the TCR?
   a. Which departments participate in obtaining all of the patient information?
   b. How do you obtain the necessary information from the various departments?
   c. Who enters the various required information for the cancer registry?
   d. Do you wait for a certain period before entering patient information? Why?
   e. How many staff work towards gathering cancer data?

2. Do you submit data electronically or manually?
   a. If you submit data manually, do you have any issues with sending data to your regional office? (For example, is it difficult to send the information via certified mail?)
   b. If you submit data electronically, do you have any issues with the export of data to the TCR? (For example, are you able to easily export the TCR data from your software, or does it take multiple steps?)

3. If you submit data manually, in which way do you submit the data?
   a. Do you submit the entire medical record?
   b. Do you submit the cancer information on the State form?
   c. Do you send it in a machine-readable format that needs interpretation or human decode?

4. If you submit data electronically, what type of software are you using to gather the cancer data?
   a. SandCrab Lite
      1. For what duration have you been using SandCrab Lite?
      2. Do you have any issues with the software in gathering cancer data and exporting it to the TCR?
      3. Do you have SandCrab Lite on a platform or are you sharing it on a network?
      4. Do you have issues with the timeliness of the SandCrab Lite technical support?
      5. How many staff access the software?
      6. How many staff are involved with the whole TCR data submission process?
      7. How is the SandCrab Lite working with your office/organization set up?
      8. How does the SandCrab Lite work for you technically? Are there any limitations?

   b. Commercially bought
      1. Who is the vendor?
      2. What is the cancer registry software called (trade or brand name)?
      3. For what duration have you been using the software?
      4. Do you have any issues with the software in gathering cancer data and exporting it to the TCR?
      5. Do you have the cancer registry software on a platform, or are you sharing it on a network?
      6. Are you able to import your medical records data directly into the cancer registry software, or do you have to enter the patient information into your medical records / billing database and then again into your cancer data software?
      7. Do you have issues with the timeliness of the software technical support?
      8. How many staff access the software?
      9. How many staff are involved with the whole TCR data submission process?

9. How is the software working with your office/organization set up?
10. How does the software work for you technically? Are there any limitations?

c. Your own created software
    1. For what duration have you been using it?
    2. What are some of the features that you enjoy about the software?
    3. What are some limiting features about the software?
    4. Are you going to resolve the limiting features in the near term?
    5. Do you have any issues with the software in gathering cancer data and exporting it to the TCR?
    6. Do you have your cancer registry software on a platform, or are you sharing it on a network?
    7. Is the cancer registry software tied to your internal medical records / billing database, do you export data from your internal medical records / billing database into your cancer registry software, or do you re-enter patient data into your cancer registry software?
    8. Do you have issues with the timeliness of your internal technical support of the software?
    9. How many staff access the software?
    10. How many staff are involved with the whole TCR data submission process?
    10. How is the software working with your office/organization set up?
    11. How does the software work for you technically? Are there any limitations?

5. What are the most pressing technical problems you face in reporting data to the TCR?
    a. Access to all of the necessary cancer information?
    b. Issues with cancer registry software?
    c. Inability to properly identify cancer cases?
    d. Other?

6. The following questions concern your opinions on the cancer data reporting process:

    a. Based on your experience, what issues do you see in terms of reporting information to the TCR, within the TCR deadlines?
    b. What issues do you see in terms of reporting all of the information required by the TCR?
    c. What issues do you see in terms of reporting accurate cancer information to the TCR?

7. In your experience, when you have had to perform audits of the cancer data either due to internal quality assurance or the regional office contacting you with a question; have you felt that the inclusion of any additional data fields in your submission would minimize your investigative efforts or the regional office call backs?
    a. Medical record number?
    b. Accession number?
    c. Other?

8. Are there any future changes in your office staffing / environment / equipment that you think will impact (positively or negatively) on the TCR reporting process?

9. Are there clear guidelines on what needs to be reported to the TCR, how it is to be reported and when?

    a. Are you able to get clear and timely answers to your questions on reporting requirements?
    b. How are changes to the guidance provided to you?

10. Are there any privacy and confidentiality requirements of the Health Insurance, Portability and Accountability Act (HIPPA), Health and Human Services (HHS), the state or your organization, that are posing technical challenges?

11. Do you think it would be beneficial to your reporting process to receive feedback from the TCR when they find errors and correct them from your cancer data submission?

12. To aid you in ensuring that you have complete patient healthcare information, would it be beneficial to receive information from the TCR on patients who have expired and any first course of therapy or additional healthcare information on a patient on whom you sent the TCR cancer data?

13. Do you end up using the final data from the TCR? How do you use the data? How do your constituents use the data?

14. If you were to offer suggestions on what could be improved with the TCR reporting process, what would your top 3 suggestions be?

C.2 Focus Group Category = End Users

1. How do you request the TCR data and how do you receive the TCR data?

2. Do you have any issues with how you request and receive the TCR data (e.g. time for delivery or report format)?

3. What do you do with the TCR data?

4. Have you found any data validity or data reliability issues in the TCR database in the past?

    a. Does the data represent input from all of the necessary reporters?
    b. Are there specific fields that you have found to be in error?
    c. Have you found instances of missing data?
    d. Do you think that the incorporation of any additional data elements in the TCR would improve the data editing process and thereby improve the data quality?
    e. Is there any data that you don't find usable due to incompleteness or lack of accuracy?
    f. What impact, if any has the data validity and reliability had on the research you do with the TCR data?

5. What are the most pressing technical problems you feel reporter's face in reporting data to the TCR?

6. The following questions concern your opinions on the cancer data reporting process:

    a. What issues do you consider impact the timely reporting of data to the TCR?
    b. What issues do you consider impact the reporting of complete information to the TCR?
    c. What issues do you consider impact the reporting of accurate information to the TCR?

7. If you were to offer suggestions on what should be improved with the TCR data request process, what would your top 3 suggestions be?

C.3 Focus Group Category = IM / IT Personnel

1. Please describe the current TCR process, including:
   a. Reporters
      - Data collection
      - Data entry into software or on hardcopy form
   b. Regional Office
      - TCR data collection
      - Electronic submissions
      - Hardcopy submissions
      - TCR quality assurance process
      - TCR error resolution process
      - TCR data entry
      - SandCrab Lite data entry
      - TCR Information storage / retrieval
      - TCR database management
      - TCR analysis process
      - Any other TCR analysis or processes
   c. Central Office
      - TCR data collection
      - Electronic submissions
      - TCR quality assurance process
      - TCR error resolution process
      - TCR data entry
      - SandCrab Lite data entry
      - TCR information storage / retrieval
      - TCR database management
      - TCR analysis process
      - TCR match with DeathNet
      - Any other TCR matching with databases
      - Any other TCR analysis or processes
      - TCR report development process

2. What are the different technical issues faced by the various TCR reporters?

3. What are the different technical issues that prevent end users from getting the TCR information they need?

4. The following questions concern the cancer data reporting process:
   a. What issues do you consider impact the timely reporting of data to the TCR?
   b. What issues do you consider impact the reporting of complete information to the TCR?
   c. What issues do you consider impact the reporting of accurate information to the TCR?

5. In your opinion are there technical barriers that could be removed to improve the current TCR error resolution process?

6. Do you feel that the incorporation of any additional data in the TCR database would ease the reporting and error resolution process?

7. What are the different technical issues faced by the TCR regional office staff?

8. What are the different technical issues faced by the TCR central office staff?

9. Are there any privacy and confidentiality requirements of HIPPA, HHS or the state that are posing technical challenges?

10. If you were to offer suggestions on what should be improved with the overall TCR process, what would your top 5 suggestions be?

C.4 Focus Group Category = Government Officials/ Funders/Regulators

1. **HIPAA implications**
   a. Are you familiar with the HIPAA Requirements for Administrative Simplification?
   b. Compliance with the initial HIPAA requirements will be mandatory in 2002 and will apply to health plans, providers, clearinghouses, and related organizations in the following areas:
      - Transactions and code sets
      - Identifiers for employers and providers
      - Security and Electronic Signatures
   c. Does the TCR currently fulfill these requirements?
   d. What are some areas for improvement for the TCR in meeting the HIPPA requirements?

2. **CDC implications**
   a. What are the CDC requirements for a cancer registry?
   b. How does the TCR fulfill these requirements?
   c. What are some areas for improvement for the TCR in meeting the CDC requirements?
   d. Based on best practices information, what are some parameters and predictors for complete, timely and accurate cancer reporting?
   e. What is the best way to implement the requirement to gather reporting from all entities?
   f. How have other states been able to incorporate pathology data?

C.5 Focus Group Category = Professional Constituent Groups

1. Do you have any general best practices information that would benefit the TCR?
   a. Data validity
   b. Data connectivity
   c. Data reliability

2. Do you have any best practices information from other disease or healthcare tracking registries in Texas that may benefit the TCR?

3. How do you request the TCR data and how do you receive the TCR data?

4. Do you have any issues with how you request and receive the TCR data?

5. What do you do with the TCR data?

6. Have you found any data validity or data reliability issues in the TCR database in the past?

   a. Does the data represent input from all of the necessary reporters?
   b. Are there specific fields that you have found to be in error?
   c. Have you found instances of missing data?

7. What are the most pressing technical problems you feel reporters face in reporting data to the TCR?

8. The following questions concern your opinions on the cancer data reporting process:

   a. What issues do you consider impact the timely reporting of data to the TCR?
   b. What issues do you consider impact the reporting of complete information to the TCR?
   c. What issues do you consider impact the reporting of accurate information to the TCR?

9. In your opinion are there technical barriers that could be removed to improve the current TCR error resolution process?

10. Do you feel that the incorporation of any additional data in the TCR database would ease the reporting and error resolution process for you?

11. If you were to offer suggestions on what should be improved with the overall TCR process, what would your top 3 suggestions be?

Appendix D: Focus Group Stem Question Contributors

The following people provided feedback on the focus group stem questions:

1. Mr. Leslie Kian (MD Anderson)
2. Dr. Melissa Bondy (MD Anderson)
3. Ms. Deidre McMillan (U.S. Oncology)
4. Ms. Rosemary McKee (Methodist Hospitals and TxTRA member)
5. Dr. Nancy Weiss (Texas Cancer Registry)
6. Ms. Jenny Young (Texas Medical Association.)
7. Dr. Billy Philips (UT Medical Branch)

Appendix E: Focus Group Members

E.1 Focus Group Category: Reporters

a. MD Anderson: Leslie Kian and Sarah Taylor (via phone conference).

b. U.S. Oncology: Deidre McMillan and Dr. Jose Lopez (oncologist) (via phone conference).

c. Baylor University Medical Center (Dallas): Carolyn Jonas, Janet Reynolds, Mary Finley, Dr. Dan Savino (pathologist), Patty Harris, and Dr. Joe Kuhn (pathologist) (all done face-to-face).

d. Baylor Medical College (Houston): Dr. Tom Wheeler (pathologist) (via phone conference).

e. Impac Medical Systems: Judy Jacobs (via phone conference).

f. Harrington Hospital: Dr. Dava Gerard (via phone conference).

g. Sierra Medical Center: Diana Miller (via phone conference).

h. Goldston Cancer Registry (Randall/Potter): Joyce Ritter Goldstein (via phone conference).

i. Shannon Medical Center: Kathy Kinney (via phone conference).

j. San Antonio Hospitals/Clinics: Rosemary McKee (Methodist Hospital), Clara Carsten (South Texas Veterans Hospital), Judy Maynard (Laredo Hospitals, Baptist Hospital), Martha Gregorich (Brooks Army Medical Center), Julissa Romero (CTRC) (all done face-to-face).

E.2 Focus Group Category: End Users

a. MD Anderson: Dr. Melissa Bondy (via phone conference).

b. American Cancer Society: Dr. Judy Jonas (via phone conference).

c. University of Texas School of Public Health: Dr. Karen Goodman, Dr. Debbie del Junco, and Dr. Sharon Cooper (via phone conference).

d. Texas Cancer Council: Ms. Mickey Jacobs (via phone conference).

e. All reporters from above provided input on end user needs.

E.3 Focus Group Category: IM/IT Personnel

a. TCR staff: Dr. Nancy Weiss, Susan Perez, John Pierce, Velma Garza, Jane Yoakum, and Vicki Cowling (all done face-to-face).

E.4 Focus Group Category: Professional Constituents

a. Scott and White: Dr. Speights (via phone conference).

b. American Cancer Society: Dr. Judy Jonas (via phone conference).

c. Texas Society of Medical Oncology: Dr. Jose Lopez (via phone conference).

E.5 Focus Group Category: Government Officials /Regulators/Funders

a. Pending state legislation on privacy.

b. HIPAA regulations.

c. Dr. John Young.

E.6 Other State Information

a. Louisiana registry staff.

b. California registry staff.

Appendix F: California Code of Regulations, Title 17

F.1 STATE DEPARTMENT OF HEALTH SERVICES

5 2593. Neoplasm, Cancer.

(a) Definitions.

(1) Department means Department of Health Services.

(2) Director means the Director of the Department of Health Services.

(3) Regional cancer registry means the organization authorized to receive and collect cancer data for a designated area of the state and which maintains the system by which the collected information is reported to the Department.

(4) Cancer means all malignant neoplasm's, including carcinoma in situ, which are specified in Volume I of the 1986 California Cancer Reporting System Standards and as set forth in the International Classification of Diseases for Oncology Field Trial Edition 1986.

(5) Case means a cancer diagnosis for an individual who is either a resident of the designated area of the regional cancer registry, regardless of where the individual was treated or diagnosed, or seen at a cancer reporting facility, other facility or by a physician within the designated area of the regional cancer registry, regardless of where the individual resides.

(6) Active follow-up program means a system for determining the vital status of each reported case no later than twelve months after the date of the last reported contact. This data is defined in Volume I of the 1986 California Cancer Reporting System Standards.

(7) Cancer reporting facility means a hospital or other facility that treats or diagnoses cancer and is also one of the following:

(A) A facility currently licensed as a health facility under the provisions of Chapter 2, commencing with Section 1250, of Division 2 of the Health and Safety Code;

(B) A surgical clinic licensed under Chapter 1. Section 1204, of Division 2 of the Health and Safety Code;

(C) A facility covered by the provisions of Section 1206, except for subsection (f), of the Health and Safety Code which, while not licensed as a clinic, is operated for the predominant purpose of diagnosing or treating cancer or where a minimum of 100 or more cancer cases were diagnosed or treated in a year.

(8) Quality Control System means operational procedures by which the accuracy, completeness and timeliness of the information reported to the Department can be determined and verified. Those criteria are defined in Volume I of the 1986 California Cancer Reporting System Standards.

(9) Certified Tumor Registrar (CTR) means the designation given to individuals who pass the certification examination given by the National Tumor Registrars Association (NTRA).

(10) Population-based means that all cases are drawn from a defined population of known size and characteristics, usually one within a defined geographic area.

(11) Cancer incidence data means information on new cases of cancer including the required data listed in the 1986 California Cancer Reporting System Standards and counts of these cases by their characteristics such as age, sex and ethnicity, and by anatomic site and morphology.

(12) Instance of cancer means case of cancer as defined in subsection (a)(5) above.

(13) Modeled after the Cancer Surveillance Program of Orange County means a population-based registry that collects treatment data, has a phased implementation, collects follow-up data, has a community advisory component and receives data in a machine-readable format from cancer reporting facilities as defined in subsection (a)(7) above.

(b) Reporting requirements. The Director shall designate cancer as a disease to be mandatorily reported for all counties within the State. All counties shall be assigned to a designated regional cancer registry. When the Director designates cancer as a disease to be mandatorily reported within an area, the Director shall designate the initial mandatory reporting period, which may be less than a full calendar year, for which the regional registry will submit cases to the Department.

(1) A regional cancer registry shall establish and maintain a cancer reporting system, which is able to report 97 percent of the incident cases in the initial designated reporting period and each calendar year.

(2) `The regional cancer registry shall have suitable arrangements to obtain data for reporting resident cases diagnosed or treated outside the designated area of the regional cancer registry.

(3) The regional cancer registry shall report to the Department all cases diagnosed or treated in a calendar year or initial reporting period within twelve months after the close of that calendar year or initial reporting period.

(4) The regional cancer registry shall submit, for each reportable case, the required data specified in Volume I Section 13, of the 1986 California Cancer Reporting System Standards.

(5) The regional cancer registry shall report to the Department all follow-up information provided by cancer reporting facilities with an active follow-up program no later than six months after the cancer reporting facility provides the information to the regional registry. In addition, each regional registry shall implement within three years of the designation of mandatory cancer reporting for the region a program of active follow-up for all resident cases not otherwise being followed by a cancer reporting facility. The results of the active follow-up program of the regional registry shall be reported to the Department quarterly.

(6) Data submitted to the Department by the regional cancer registry shall be in machine-readable form. The format and codes used shall be as specified by the Department.

(7) The regional cancer registry shall maintain a system of quality control in accordance with procedures approved by the Department.

(8) Representatives of the Department shall have access to the source data and the stored data in the regional cancer registry for the purpose of quality control assessments. This includes access to all cancer records maintained by a reporting facility, physician individual or agency providing diagnostic or treatment services to cancer patients within the region.

(9) The regional cancer registry shall maintain confidentiality of data as required in Section 211.5, Health and Safety Code, and shall maintain a security system for records which contain identifying data. This system shall be reviewed and approved by the Department.

(10) When cancer is designated a reportable disease in a region, the corresponding regional cancer registry shall inform the public that cancer has been designated as a disease required to be reported in that region and that each patient diagnosed or treated with a Reportable Neoplasm will be reported to the Department as required by law.

(11) Cancer reporting facilities within a reporting region shall report to the regional cancer registry the required data as listed in Volumes I and III of the 1986 California Cancer Reporting System Standards. These reports shall conform to Volumes I, II, and III of the 1986 California Cancer Reporting System Standards. When a cancer reporting facility fails to produce reports meeting the standards cited above, the regional cancer registry may perform the data collection and collect compensation from the facility for the activity at cost.

(12) Cancer reporting facilities shall report to their regional cancer registry each reportable case within six months of the time the case comes under the care of, or is admitted to, the facility.

(13) Cancer reporting facilities with an active follow-up program shall report follow-up information to the regional cancer registry no less frequently than quarterly.

(14) A facility not already defined as a cancer reporting facility under these regulations which diagnoses or treats cancer and is a primary care clinic as defined in Section 1204, Health and Safety Code or an acute psychiatric hospital as defined in Section 1250, Health and Safety Code shall report each cancer case to its regional cancer ;,&y, or to the local health department, the choice to be determined by the regional registry, using the Confidential Morbidity Report (Form PM-l lo), shown below, within 30 days of the date the patient is admitted to the facility or treated in the facility for the first time. These reports shall conform to California Cancer Reporting System Standards, Volume IV.

(15) Physicians and surgeons caring for cancer patients not referred to a facility defined as a cancer reporting facility under these regulations shall report each cancer case to the regional cancer registry or to the local health department, the choice to be determined by the regional registry, using the Confidential Morbidity Report (PM- 1 lo), within 30 days of seeing the patient for the cancer for the first time. These reports shall conform to California Cancer Reporting System Standards, Volume IV.

(16) Cancer reporting facilities shall submit their cancer cases and follow-up information to the regional cancer registry in machine-readable form. The format and codes used shall be as specified by the Department in the 1986 California Cancer Reporting System Standards Volume II.

(17) Cancer reporting facilities may elect to have the regional cancer registry staff do the cancer data collection. They may do so by a contract with the regional cancer registry to identify and report the cancer cases with the facility reimbursing the regional registry for that registry's expense.

(18) Cancer reporting facilities and physicians shall employ a mechanism to ensure that their patients are informed that cancer has been designated a reportable disease and that the facility will report each patient with cancer to the Department as required by law. Patient information sheets for this purpose will be supplied to physicians by the Department.

(c) Staffing. The identification and collection of cancer data in the regional cancer registries and cancer reporting facilities shall be performed by Certified Tumor Registrars (CTR) or staff eligible to take the certification examination.

(d) Training and Credentialing Period. Reporting facilities so requesting upon application to the regional registry, may be granted a credentialing period of up to 24 moths for the purpose of obtaining training to meet the requirements set forth in subsection (c) above. No credentialing period may be granted to extend beyond 30 months from the effective date to mandatory cancer reporting for the region or beyond July 1, 1990. During a credentialing period the reporting facility must meet the quality and other reporting standards. It is the responsibility of the Department, which may be carried out by the regional cancer registries, to assure that adequate tumor registrar training resources are available for no less than 24 months following the initiation of mandatory reporting in a region.

(e) Designation of Agent. The Director may designate the contract with any agency to act as the Department's agent for ed agent shall comply with all regulations of the regional cancer registry.

(f) Revocation of Designation. The Director shall have the authority to revoke the designation as Department agent. Revocation shall be effective no sooner than 30 days after a written notice to revoke the designation has been served.

NOTE: Authority cited: Sections 208,210 and 211.3, Health and Safety Code. Reference: Sections 2 10,2 11.3 and 2 11 S, Health and Safety Code

History

1. New section filed 3-20-8 1; effective thirtieth day thereafter (Register 8 1, No. 12).
2. Amendment filed 1 l-2-87; operative 12-2-87 (Register 87, No. 45)